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Report of the Special Rapporteur on the rights of persons with disabilities

Note by the Secretariat

The Secretariat has the honour to transmit to the Human Rights Council the report of the Special Rapporteur on the rights of persons with disabilities, pursuant to Council resolutions 26/20 and 35/6. In her report, the Special Rapporteur provides an overview of the activities undertaken in 2017 and a thematic study on the right of persons with disabilities to equal recognition before the law. The study provides guidance to States on how to guarantee this right for persons with disabilities, paying particular attention to the process of law reform on legal capacity.

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I. Introduction

1. The Special Rapporteur on the rights of persons with disabilities, Catalina Devandas Aguilar, submits the present report to the Human Rights Council pursuant to Council resolutions 26/20 and 35/6. It contains a description of the activities she carried out in 2017 and a thematic study on the right of persons with disabilities to equal recognition as a person before the law. In preparing the study, the Special Rapporteur analysed the responses to a questionnaire sent to Member States, national human rights institutions, agencies of the United Nations system, civil society organizations and persons with disabilities and their representative organizations. She received 40 responses.[1] She also relied on information gathered during an expert meeting on supporting the autonomy and independence of older persons with disabilities, which took place in New York in October 2017.

II. Activities of the Special Rapporteur

A. Country visits

2. In 2017, the Special Rapporteur visited the Democratic People's Republic of Korea from 3 to 8 May (A/HRC/37/56/Add.1), Kazakhstan from 4 to 12 September (A/HRC/37/56/Add.2) and France from 3 to 13 October (report to be submitted to the fortieth session of the Council). She thanks the Governments concerned for their cooperation prior to, during and after the visit.

3. The Special Rapporteur has agreed to undertake a visit to Kuwait during the last quarter of 2018 and has requested invitations to visit Cambodia, Chile, Colombia and Saudi Arabia. She has also received an invitation to visit Algeria and Egypt.

B. Engagement with stakeholders

4. During the year, the Special Rapporteur participated in numerous conferences and expert meetings, including the fifty-fifth session of the Commission for Social Development in New York in February, the fifth Pacific Regional Conference on Disability in Samoa, also in February, and the annual interactive debate on the rights of persons with disabilities at the Human Rights Council in March. She also co-organized expert consultations on disability assessment and on sexual and reproductive health and rights of girls and young women with disabilities jointly with other United Nations experts, agencies, international civil society organizations, organizations of persons with disabilities and academia. She actively promoted the establishment of a United Nations system-wide action plan on disability with the Inter-Agency Support Group for the Convention on the Rights of Persons with Disabilities.

5. In June, she participated in the tenth session of the Conference of States Parties to the Convention on the Rights of Persons with Disabilities, and its parallel events. As mandated by the General Assembly, she continued to engage with the United Nations Statistical Division, the Inter-Agency and Expert Group on Sustainable Development Goal Indicators and several United Nations agencies to advocate for the use of the short set of questions of the Washington Group on Disability Statistics to disaggregate data by disability in the monitoring of the Sustainable Development Goals.

6. In July, she organized a meeting in Madrid with United Nations human rights experts to discuss the role of human rights mechanisms (treaty bodies and special procedures) to protect the rights of persons with disabilities and identify ways to enhance coherence and coordination in this area. In October, together with the Independent Expert

[1] See www.ohchr.org/EN/Issues/Disability/SRDisabilities/Pages/LibertyAndSecurity.aspx.

on the enjoyment of all human rights by older persons, she convened international experts from the ageing and disability constituencies to discuss the situation of older persons with disabilities, particularly as it relates to their autonomy and independence.

7. On 24 October, the Special Rapporteur presented her annual report to the General Assembly on sexual and reproductive health and rights of girls and young women with disabilities (A/72/133). The report was made available in accessible formats.

8. On 4 December, to mark the International Day of Persons with Disabilities, the Special Rapporteur together with other United Nations agencies, Member States and disability advocacy organizations organized several awareness-raising activities under the campaign to embrace diversity called "A Day for All". In December, she also took part in the celebrations of the twentieth anniversary of the Convention on the Prohibition of the Use, Stockpiling, Production and Transfer of Anti-Personnel Mines and on Their Destruction held in Vienna.

9. In June, the Special Rapporteur was elected as Chair of the Coordination Committee of Special Procedures and held many meetings in that capacity. She continued to collaborate closely with special procedures and treaty bodies, as well as with other United Nations experts and agencies, including the International Labour Organization, the Office of the United Nations High Commissioner for Human Rights, the United Nations Population Fund, the World Health Organization and the United Nations Partnership to Promote the Rights of Persons with Disabilities.

10. The Special Rapporteur also engaged with several stakeholders, such as national human rights institutions, representative organizations of persons with disabilities, other non-governmental organizations, universities and the diplomatic community.

C. Communications

11. Summaries of communications sent and replies received during the period covered by the present report are available in the communications reports of special procedures (A/HRC/34/75, A/HRC/35/44 and A/HRC/36/25).

III. The right of persons with disabilities to equal recognition before the law

12. The present report aims to provide guidance to States on how to guarantee the right of persons with disabilities to equal recognition before the law. Given the importance of the process of legal harmonization in implementing that right, the report pays particular attention to the process of law reform on legal capacity.

A. A paradigm shift towards universal legal capacity

13. Equal recognition before the law is central to human rights. Often described as the "right to have rights", it articulates the right of every person to be a holder of rights and obligations under the law, which is a necessary precondition for the exercise of all other human rights and fundamental freedoms. At the international level, it is recognized in the Universal Declaration of Human Rights (art. 6), the International Covenant on Civil and Political Rights (art. 16), the Convention on the Elimination of All Forms of Discrimination against Women (art. 15), the International Convention on the Protection of the Rights of All Migrant Workers and Members of their Families (art. 24) and the Convention on the Rights of Persons with Disabilities (art. 12).[1] At the regional level, it is recognized in the American

[1] While the Convention on the Rights of the Child does not contain any explicit provision, the recognition of children as rights holders and respect for their views and interests are intrinsic to its text.

Convention on Human Rights (art. 3) and the African Charter on Human and Peoples' Rights (art. 5).

14. Recognition as a person before the law and legal capacity are closely interlinked concepts. Equal recognition as a person before the law guarantees the right of every human being to have his or her existence recognized in the legal order, that is, being recognized as possessing legal personality and coming within the purview and protection of the law. Legal capacity entails holding rights and duties (legal standing) and exercising those rights and duties (legal agency).[3] The evolving interpretation of the right to equal recognition as a person before the law implies that legal capacity is a universal attribute inherent to all persons by virtue of their humanity. Therefore, if a person's legal agency is denied, his or her status as a person before the law is also affected.

15. Throughout history, many groups have been denied their legal capacity as both legal standing and legal agency, including women, minority groups, indigenous persons, migrants, refugees and asylum seekers. Among them, persons with disabilities face a wide range of violations to their right to legal capacity in all jurisdictions worldwide. Challenges are particularly acute for persons with psychosocial disabilities, persons with intellectual disabilities, autistic persons and persons with dementia. Their legal capacity is usually restricted on the basis of having a medical condition or impairment (status approach), having made a decision perceived as poor (outcome approach), or having deficient decision-making skills (functional approach).[4] Once their legal capacity is restricted in one or more areas of life, they are put under a substitute decision-making regime such as guardianship or curatorship, where a legal representative is appointed to make decisions on their behalf, or where decisions will be made by designated medical personnel or by a court.

16. The denial of and restrictions to the legal capacity of persons with disabilities are grave and pervade all aspects of life. Persons with disabilities under guardianship, for example, lose their capacity to exercise all or almost all of their rights and have no control over decisions related to their lives, from entering into contracts to choosing where and with whom to live. Restrictions may also apply on a case-by-case basis. For example, legislation based on a functional approach may limit a person's rights and freedoms in specific areas of life such as marriage, voting, parenting or free and informed consent to health care. Furthermore, in many jurisdictions, those who have not been formally placed under any form of substituted decision-making may also face restrictions in exercising their rights, as it is commonly assumed that they have no legal capacity or that they need a third person to validate their acts. All those practices perpetuate discrimination and exclusion against persons with disabilities, and pave the way to different forms of abuse, corruption, exploitation, coercion and institutionalization.

17. Women with disabilities experience aggravated forms of discrimination and specific violations against their right to legal capacity. Owing to gender stereotypes and gender-based violence, they are at particularly high risk of being placed under substitute decision-making regimes. For instance, women with leprosy-related disabilities are often deprived of rights, such as the right to property. Furthermore, in most countries, women with disabilities cannot take autonomous decisions with regard to their reproductive and sexual health and rights, resulting in highly discriminatory and harmful practices (A/72/133).

18. Similarly, older persons with disabilities are at heightened risk of being denied or restricted in their legal capacity, formally or informally, owing to prejudices and assumptions based on both age and disability. Many of them are placed in institutions, confined at home or are not allowed to exercise their legal capacity without the consent of family members, even if there is no substitute decision-making regime in place. These

[3] See Committee on the Rights of Persons with Disabilities, general comment No. 1 (2014) on equal recognition before the law, paras. 11–12.

[4] Amita Dhanda, "Legal capacity in the Disability Rights Convention: stranglehold of the past or lodestar for the future?", *Syracuse Journal of International Law and Commerce*, vol. 34, No. 2 (2007).

practices lead to the loss of control of their lives and expose older persons with disabilities to high levels of violence, abuse and neglect.

19. For too long, the international human rights system did not pay attention to those multiple violations of the right to legal capacity of persons with disabilities. In fact, there has been a significant underuse of the international legal framework to advance this and other human rights for persons with disabilities (see A/70/297, para. 18).

20. In that context, the Convention on the Rights of Persons with Disabilities introduces a paradigm shift in relation to the legal capacity of persons with disabilities. The Convention moves away from medical and paternalistic approaches to disability towards a human rights-based approach and considers persons with disabilities as rights holders, rather than as mere receivers of protection, rehabilitation or welfare. In the Convention the universality, indivisibility, interdependence and interrelatedness of human rights are recalled by stressing that persons with disabilities should fully enjoy all their rights without any kind of discrimination. While in the text of the Convention the subsistence of structures and practices that are contrary to the human rights of persons with disabilities is questioned, the importance of positive measures to ensure the effective implementation of the Convention is also stressed.

21. In the Convention a universalist understanding of the right to legal capacity is upheld and it states that all persons with disabilities enjoy legal capacity on an equal basis with others. Moreover, the role of support in the actual implementation of the right to legal capacity is emphasized, underlining the diversity and interdependence of human experiences. Accordingly, persons with disabilities should have access to appropriate support to exercise their legal capacity and not be restricted in its enjoyment. The paradigm of the Convention enshrines the universal recognition of legal capacity and the provision of the support needed to exercise it. In doing so, it challenges traditional discriminatory approaches and acknowledges the structural barriers to exercising legal capacity experienced by persons with disabilities. Furthermore, the Convention has expanded the understanding of the right to equal recognition before the law in the international human rights system for persons with disabilities and other groups.[5] On that account, the obligations arising from other international human rights treaties should be complemented by the provisions of the Convention and interpreted in the light of it.

22. The paradigm shift of the Convention in relation to legal capacity has already had an important impact on the work of the United Nations and of regional organizations. Different United Nations treaty bodies, special procedures and agencies are progressively adjusting their standards to the Convention.[6] In the inter-American human rights system, the Committee for the Elimination of All Forms of Discrimination against Persons with Disabilities adopted a general comment calling for the Inter-American Convention for the Elimination of All Forms of Discrimination against Persons with Disabilities to be interpreted in line with article 12 of the Convention on the Rights of Persons with Disabilities.[7] The draft protocol to the African Charter on Human and Peoples' Rights on the rights of persons with disabilities in Africa, adopted in 2016, also recognizes the right to legal capacity of all persons with disabilities.

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[5] For example, in the Inter-American Convention on Protecting the Human Rights of Older Persons the support paradigm of the Convention on the Rights of Persons with Disabilities in relation to the right to equal recognition before the law is upheld. The Committee on the Rights of the Child has also referred to the need to ensure access to supported decision-making arrangements to ensure the right of children to express their views (see general comment No. 20 (2016) on the implementation of the rights of the child during adolescence, paras. 22 and 32).

[6] See, for example, E/C.12/MDA/CO/2, para. 24, Committee on the Elimination of Discrimination against Women, general recommendation No. 35 (2017) on gender-based violence against women, updating general recommendation No. 19, para. 29; CEDAW/C/CZE/CO/6, para. 41; CEDAW/C/MDA/CO/4-5, para. 38; CEDAW/C/FIN/CO/7, para. 29; CEDAW/C/IND/CO/4-5, para. 37; A/HRC/10/48, paras. 43–47; and A/HRC/34/32, paras. 25–28. See also WHO QualityRights guidance and training tools, available from www.who.int/mental_health/policy/quality_rights/en/.

[7] See OEA/Ser.L/XXIV.3.1 CEDDIS/doc.12 (I-E/11).

B. The normative content of article 12 of the Convention on the Rights of Persons with Disabilities

23. Article 12 of the Convention articulates the content of the right to equality before the law as it applies to persons with disabilities. Article 12 (1) reaffirms the right of persons with disabilities to be recognized as persons before the law. Article 12 (2) recognizes that persons with disabilities enjoy legal capacity on an equal basis with others in all areas of life. Article 12 (3) sets out the State obligation to provide persons with disabilities with access to support in the exercise of their legal capacity. Article 12 (4) outlines the safeguards that must be present in a system of support for the exercise of legal capacity. Finally, article 12 (5) requires States to ensure the rights of persons with disabilities with respect to financial and economic affairs, on an equal basis with others.

24. There are four primary State obligations arising from article 12. First, States must recognise universal legal capacity for all persons with disabilities, including for those requiring more intensive support. That entails adopting legislation that explicitly recognizes the capacity of persons with disabilities to create, modify or end legal relationships, as well as providing effective legal protection against any interference with such capacity. That recognition must include the exercise of the right to property, access to all forms of financial credit and the right to control one's own financial affairs, as recognized in article 12 (5) of the Convention. States cannot restrict the legal capacity of persons with disabilities and must rather protect it against any interference in all aspects of life, including decisions related to medical treatment, living independently or financial matters.

25. The recognition of universal legal capacity for all persons with disabilities strongly influences the exercise of all other human rights and fundamental freedoms. Those rights include access to justice (art. 13 of the Convention), liberty and security of the person (art. 14), freedom from torture or cruel, inhuman or degrading treatment or punishment (art. 15), freedom from exploitation, violence and abuse (art. 16), integrity (art. 17), nationality and liberty of movement (art. 18), living independently and being included in the community (art. 19), freedom of expression and opinion, access to information (art. 21), privacy (art. 22), marriage, family, parenthood and relationships (art. 23), health, including the right to free and informed consent (art. 25), work and employment (art. 27), adequate standard of living and social protection (art. 28), and participation in political and public life (art. 29). States must eliminate, in law and practice, all denials or restrictions of legal capacity of persons with disabilities in the exercise of these rights.

26. Second, States must abolish and prohibit all regimes of substituted decision-making. According to the Committee on the Rights of Persons with Disabilities, these regimes can be defined as systems where legal capacity is removed from a person (even if limited to a single decision) and a substitute decision maker appointed by a third party takes decisions based on what he or she considers is in the best interests of the person concerned, even if that goes against the will of the latter.[8] They include plenary and partial guardianship, judicial interdiction, curatorship, conservatorship and mental health laws that allow involuntary treatment and commitment. All forms of substitute decision-making are prohibited under the Convention, including those based on the assessment of mental capacity skills.[9]

27. Third, States must develop supported decision-making arrangements of varying types and intensity, including informal and formal support arrangements.[10] Such arrangements include, for example, support networks, support agreements, peer and self-support groups, support for self-advocacy, independent advocacy and advance directives. Contrary to substitute decision-making regimes, under a supported decision-making arrangement, legal capacity is never removed or restricted; a supporter cannot be appointed by a third party against the will of the person concerned; and support must be provided based on the will and preferences of the individual. The right to legal capacity is not

[8] Committee on the Rights of Persons with Disabilities, general comment No. 1, para. 27.
[9] Ibid., para. 15.
[10] Ibid., para. 17.

contingent on the acceptance of any form of support or accommodation, as persons with disabilities have the right to refuse them.[11]

28. All forms of support must incorporate a human rights based-approach that is respectful of the general principles of the Convention (art. 3). States must take all appropriate measures to ensure that support programmes respect the inherent dignity, individual autonomy (including the freedom to make one's own choices), and independence of persons; are provided on a voluntary basis; and respect the principles of non-discrimination and equality. Support arrangements should be designed to enable direct choice and control by persons with disabilities, so that they can plan and direct their own support (see A/HRC/34/58, para. 55). Furthermore, States must adopt a community-based approach to the provision of support. That allows the provision of culturally sensitive support arrangements in the communities where persons with disabilities live, builds on existing social networks and community resources, and enables stakeholders (family, friends, neighbours, peers and others) to play a significant role in supporting persons with disabilities (see A/HRC/34/58, para. 61).

29. Support arrangements must be available, accessible, adequate and affordable (see A/HRC/34/58, paras. 48–56). States should ensure the availability of an adequate number of functioning programmes and services to provide the fullest possible range of support to the diverse population of persons with disabilities. Support arrangements should also be accessible to all persons with disabilities, particularly the most disadvantaged ones, without discrimination of any kind. States must ensure that support is available within the safe physical and geographical reach of everyone, including those in institutions. Support must be affordable for all persons with disabilities, and States must ensure that support is available at nominal or no cost to the maximum extent of their available resources and take into account gender disparities in income and access to financial resources. States are also required to provide accessibility measures and reasonable accommodation to ensure that persons with disabilities can exercise legal capacity. The State obligation to ensure access to support goes beyond the right to legal capacity, as some persons with disabilities may need support for decisions that have no legal impact (see A/HRC/34/58, paras. 29–41).

30. Fourth, States must establish safeguards to ensure the respect for the rights, will and preferences of the individual who is availing themselves of that support. Safeguards on the provision of support must: (a) be based on the person's rights, will and preferences; (b) offer protection against abuse and undue influence; and (c) be proportional and tailored to the individual. Safeguards should include accountability mechanisms to ensure that the person's will and preferences are respected in the provision of support, as well as mechanisms to challenge the action of a support person if there is a belief that the support person is not acting in accordance with the will and preferences of the person concerned. Ensuring that persons with disabilities have access to different forms of support, including independent advice, also contributes to reducing the risk of undue influence. It is important to emphasize that safeguards are meant to protect individuals in the provision of support, not prevent them from making decisions, or from the possibility of taking risks and making mistakes. Support should never amount to substitute decision-making and the primary purpose of the safeguards outlined in article 12 of the Convention is to ensure the respect of the rights, will and preferences of the person concerned.[12]

31. The Special Rapporteur acknowledges that in certain situations the will of the person concerned might be difficult to determine. In situations where this cannot be established even after significant efforts, including through the provision of support and accommodations, a "best interpretation of the will and preference" standard should be applied as a last resort.[13] That standard implies ascertaining what the person would have wanted instead of deciding on the basis of her/his best interest. The process should include consideration of the previously manifested preferences, values, attitudes, narratives and actions, inclusive of verbal or non-verbal communication, of the person concerned.

[11] Ibid., para. 29 (g).
[12] Ibid., para. 20.
[13] Ibid., para. 21.

32. Similarly, the provision of support to persons experiencing an emotional crisis and severe distress poses certain difficulties. The default response in most jurisdictions today is to override the legal capacity of the person concerned and to authorize forced psychiatric interventions. However, such an approach does not respect the inherent dignity and autonomy of the individual. The support paradigm offers a rights-based approach to deal with such cases. For instance, advance plans allow persons with disabilities to give instructions on how to deal with future emotional crises and/or to appoint a person to support them in those particular circumstances. In addition, there is growing evidence as to the effectiveness of non-coercive support practices within and outside the health sector (see A/HRC/35/21, para. 29). Those practices need to be further researched, developed and implemented, and must be based on the principles set out above regarding supported decision-making. In addition, there is an urgent need to address the structural aspects that make it impossible for persons with disabilities to access support during an emotional crisis (for example, because of prejudice, low expectations, lack of flexibility, lack of resources or stringent liability).

33. Article 12 of the Convention was one of the most discussed articles and the one that demanded the greatest consensus during the negotiations. The issues of universal legal capacity and substituted decision-making were discussed extensively during the drafting process. The text adopted reflects the common understanding that all persons with disabilities should enjoy the right to legal capacity on an equal basis with others, as well as the right to access support if requested. In fact, proposals to limit the scope of the right to legal capacity and to incorporate a substituted decision-making paradigm, including the proposal to include a footnote conditioning the understanding of the term legal capacity in several languages, were rejected prior to the adoption of the Convention.

IV. Legal capacity law reform

34. Under international human rights law, States have an obligation to respect, protect and fulfil the right of all persons with disabilities to legal capacity. The obligation to respect means that States should refrain from interfering with or curtailing, by any means, the enjoyment of persons with disabilities of the right to legal capacity. The obligation to protect requires States to prevent third parties, including private actors, from interfering with persons with disabilities to realize and enjoy the right to legal capacity. The obligation to fulfil requires States to take positive actions to facilitate the exercise of their legal capacity, including by facilitating access to support and training.

35. International human rights law also imposes on States an obligation to ensure that their domestic legislation is consistent with international standards. Article 4 (1) (a) and (b) of the Convention requires States to adopt all the appropriate legislative measures to implement the human rights and fundamental freedoms recognized therein and to repeal any inconsistent legislation that constitutes discrimination against persons with disabilities. States must therefore review the adequacy of their existing legislation in view of their obligations under article 12 and other related articles of the Convention.

36. Accordingly, States should identify all legislation to be abolished, amended or adopted to render their normative framework compliant with article 12 of the Convention. The legal review should be comprehensive and take into account the interdependence and indivisibility of all human rights. It should also be all-encompassing and exhaustive, going beyond the traditional areas of law related to legal capacity (civil, family and mental health law), to include legislation on political participation, privacy, health, employment, social protection, immigration, criminal law and access to justice, among other things.

37. Thirteen States parties to the Convention have issued reservations and declarations[14] upon ratification or accession, with the intention of limiting the implementation of article

[14] The Special Rapporteur considers such declarations as reservations, since they aim to exclude or modify the legal effect of the provisions of the Convention.

12 and other related articles.[15] According to article 19 of the Vienna Convention on the Law of Treaties and article 46 of the Convention itself, reservations and declarations incompatible with the object and purpose of the Convention are not permitted. Given the centrality of article 12 to the enjoyment and exercise of all rights set out in the Convention, such restrictions clearly contradict the object and purpose of the Convention, as they hinder and/or deny the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities. In that regard, the Special Rapporteur urges the States parties concerned to withdraw all their reservations and declarations.

A. Law reform trends on legal capacity and supported decision-making

38. Since the adoption of the Convention, several States[16] have started or completed legal reforms in relation to the right to legal capacity of persons with disabilities as part of their obligations under the Convention, or in order to harmonize their legislation prior to ratification or accession. While most of these laws and bills are not in full compliance with article 12 of the Convention, they show that a growing number of States acknowledge that their legal systems, and particularly their substitute decision-making regimes, fail to guarantee the rights of persons with disabilities.

39. In 2016, Costa Rica adopted Law No. 9379, which abolished all forms of guardianship and created the legal figure of "guarantor for the equality before the law of persons with disabilities", whose role is to ensure the full enjoyment of legal capacity by all persons with disabilities. The Special Rapporteur welcomes this significant development and encourages Costa Rica to promptly adopt the necessary regulations to effectively implement the reform in line with the principles and rights of the Convention.

40. Some countries have adopted provisions declaring universal legal capacity for persons with disabilities. Those declarations reaffirm that persons with disabilities have the right to equal recognition before the law and legal capacity, as enshrined in article 12 of the Convention. While those declarations often contradict other provisions in the same legal framework, they open the space for further law reforms and court interventions. For example, in the general law on persons with disabilities of Peru a universal recognition of legal capacity was introduced and at the same time a parliamentary committee was created to review the Civil Code in line with the declaration in the general law.

41. Several countries have also introduced recognition of supported decision-making regimes into their legislation. The scope and formality of those regimes vary from country to country, but generally they allow individuals to appoint one or more persons to assist them to: (a) obtain and understand information, (b) evaluate the possible alternatives and consequences of a decision, (c) express and communicate a decision, and/or (d) implement a decision. In some jurisdictions, however, the role of supporters includes representation as a general rule, which renders the support as a de facto mechanism of substitute decision-making.

42. In a number of countries, persons with disabilities must access the courts in order to have supported decision-making arrangements recognized. The courts are mandated either to determine the scope of such arrangements, or to ensure that the proposed scope is suitable. While in most cases such measures have no impact on a person's legal capacity, requiring the intervention of a court creates a series of challenges for persons with disabilities: (a) in most jurisdictions they encounter barriers in access to justice owing to the

[15] Australia, Canada, Egypt, Estonia, France, Georgia, Kuwait, Malaysia, Netherlands, Norway, Poland, Singapore and Venezuela (Bolivarian Republic of).

[16] The Special Rapporteur identified law reform processes, which do not include mental health legislation, in at least 32 countries: Argentina, Australia (New South Wales, Northern Territory and Victoria), Austria, Belgium, Bulgaria, Canada (Alberta), Colombia, Costa Rica, Czechia, Denmark, Germany, Georgia, Hungary, Ireland, Israel, India, Kenya, Latvia, Lithuania, Malta, Marshall Islands, Netherlands, Peru, Portugal, Republic of Moldova, Romania, Russian Federation, Spain (Catalonia), Switzerland, United Kingdom of Great Britain and Northern Ireland (Northern Ireland), United States of America (Texas) and Zambia.

lack of accessibility and procedural accommodations; (b) it is a more costly system, which makes access to support less affordable; (c) court delays can compromise access to support; and (d) intense training is required to ensure a paradigm shift in the way judges address the legal capacity of persons with disabilities.

43. In some countries, persons with disabilities can create supported decision-making arrangements through private agreements. Such regimes are voluntary and can be terminated at any time. While those agreements do not require judicial intervention, in many jurisdictions they are usually subject to very rigorous validity requirements and must be notarized and/or registered in order to have legal effect and be monitored. As the procedure can compromise the confidentiality of personal information and could be wrongly perceived as a condition for exercising legal capacity, it requires appropriate regulation to ensure adequate safeguards to avoid compromising the full exercise of legal capacity.

44. Many legal systems also provide for advance directives, which allow individuals to express their will and preferences beforehand, so they can be followed at a time when they may not be in a position to communicate them. The scope of the potential advance decisions is usually specified in each jurisdiction. Advanced health-care directives are among the most common, but some countries allow advanced directives with a broader scope, including personal, patrimonial or finance matters (enduring power of attorney). The person concerned should decide the moment in which an advance directive enters into force and ceases to have effect.[17] However, in most jurisdictions advance directives only enter into force when the person is declared legally incapacitated. Moreover, in many countries they are not binding or can be overruled in certain situations.

45. Some countries have implemented regimes of co-decision-making. Under those regimes, an individual appoints a co-decision maker who will make decisions jointly with the appointer in order for those decisions to have legal effect. Such arrangements are usually implemented through private agreements, although some legal frameworks require court intervention. In most jurisdictions, however, the co-decision maker has the power, in certain circumstances, to veto a person's decision, thus restricting the exercise of their legal capacity. As long as such arrangements are involuntary and the person concerned does not have the right to terminate or change the relationship at any time, the directives cannot be considered as a form of supported decision-making.

46. States have also introduced independent advocates to support persons with disabilities to exercise their legal capacity. In Sweden, for example, independent advocates, called "personal ombudsmen", conduct outreach and establish relationships of trust with persons with psychosocial disabilities, providing them support in different areas of life, including decision-making. Research has shown that this nationwide scheme provides significant benefits not only to its clients but also to society in general, by reducing the use and the costs of specialized services.[18] In some jurisdictions, however, independent advocates work within the framework of substituted decision-making regimes, assisting individuals who have been deprived of their legal capacity to express their will and preferences and/or to communicate with the guardian or curator.

47. All supported decision-making regimes include a broad range of safeguards. Many jurisdictions require supporters to respect the will and preferences of the individuals, while regretfully others still refer to the "best interest" standard. Several countries have incorporated provisions in their laws to prevent abuses and undue influence, such as time limits, periodic review, requirements for being a supporter, liability, complaint and redress mechanisms, and monitoring. For example, in Ireland the Assisted Decision-Making (Capacity) Act 2015, provides that anyone can lodge an administrative complaint against a decision-making assistant.

48. Many of the efforts towards supported decision-making regimes maintain elements of substitute decision-making and/or coexist with regimes of substitute decision-making. In

[17] See Committee on the Rights of Persons with Disabilities, general comment No. 1, para. 17.

[18] See Sverige Socialstyrelsen, "A new profession is born: personligt ombud, PO" (2008), p. 24.

some jurisdictions, courts can impose a supported decision-making arrangement or a co-decision-making arrangement, or decide who should act as a supporter and what acts she or he may perform. Many countries have established thresholds to access support, usually based on an assessment of a person's mental capacity, where those who cannot reach such thresholds are "doomed" to substitution decision-making regimes. The use of the "best interest" standard in some supported decision-making regimes is also worrisome, as it contradicts respect for the will and preference of individuals. Furthermore, in certain jurisdictions, accessing certain forms of supported decision-making compromises the legal capacity of the person and can translate into a loss of rights, including parental and political rights.

49. Despite such limitations, the growing number of countries adopting supported decision-making schemes is encouraging and shows that substitute decision-making regimes are increasingly being challenged. Colombia and Peru, for example, are in the process of undertaking major legal reforms in this area, which include the recognition of the capacity to act of all persons with disabilities, the elimination of guardianship regimes, and the introduction of a set of supported decision-making arrangements. In both countries, draft bills prepared by multi-stakeholder commissions received the endorsement of different political parties and civil society. The Special Rapporteur welcomes those processes and strongly encourages the States to promptly adopt these important reforms.

50. The Special Rapporteur has also identified countries that have undertaken reforms to ensure more procedural safeguards in the implementation of substitute decision-making regimes. Changes introduced include the possibility to choose the person who would act as guardian, the periodic review of guardianship orders and the right to appeal decisions that remove or restrict one's legal capacity. Some countries have also limited guardianship to being a measure of last resort, when no other less restrictive measure can be applied. All such reforms fall short in respecting the rights of persons with disabilities, as the existence of substitute decision-making regimes is contrary to article 12 of the Convention.

51. In a similar effort, a number of countries have removed plenary guardianship entirely from their legal systems, only permitting substitute decision-making in certain circumstances and for a limited period of time. In the majority of cases, States transition from plenary guardianship to partial guardianship or curatorship, limiting restrictions to legal capacity to health and/or financial matters. While the abolition of plenary guardianship is an important step, maintaining or creating regimes of partial guardianship and other forms of substitute decision-making are still contrary to the requirements of article 12 of the Convention.

52. Finally, there are a significant number of countries that have adopted or are considering adopting mental health legislation. As long as mental health laws allow for the involuntary deprivation of liberty, forced treatment and forced medication of persons with disabilities, those laws are contrary to the Convention, including the right of persons with disabilities to legal capacity. Regardless of their rights-based rhetoric and increased procedural safeguards, mental health laws confer on medical professionals the capacity to make decisions on behalf of persons with disabilities, particularly persons with psychosocial disabilities, thus legitimizing coercive practices. Moreover, in the past two decades, there has been a worrisome increase of community treatment orders in mental health legislation, which expands coercive care beyond the confines of mental health facilities.[19] Mental health legislation as it exists today must be repealed, as it creates a separate legal regime for persons with psychosocial disabilities, contrary to the obligations of States under the Convention. Regulation of the practice of mental health services should focus on acceptability and quality, while the rights and freedoms of persons with psychosocial disabilities must be the same as those of others in all areas of law, including legal capacity and liberty and security of the person.

[19] See Andrew Molodynsky, Jorun Rugkåsa, and Tom Burns, *Coercion in Community Mental Health Care*: International Perspectives (Oxford, Oxford University Press, 2016).

B. Learning from supported decision-making in practice

53. Since the adoption of the Convention, there has been an increased interest in exploring how supported decision-making works in practice; pilot projects have been carried out in a number of countries across the world.[39] Some have been carried out or funded by States, whereas others have been directly implemented by civil society organizations, including organizations of persons with disabilities, parent organizations and research centres. These initiatives cover a rich and diverse range of experiences and constitute a valuable source of information for legislators and policymakers.

54. The different models of supported decision-making include, among others, formal and informal networks, support agreements, independent advocates, peer support, advance directives and personal assistance. Such schemes provide a very broad range of support to individuals, including access to information, support for communication, empowerment, building self-confidence, relationship building, personal planning, independent living assistance and administrative support. Moreover, while in many jurisdictions supported decision-making involves the appointment of one or more individuals, in practice support is also provided in group settings or using a mixed structure that incorporates both individual and group support. Legislation needs to acknowledge this diversity in supported decision-making regimes. However, there is little recognition of peer support in legislation, despite its potential to assist persons with disabilities in exercising their legal capacity.

55. Most supported decision-making schemes reviewed for the present report tend to concentrate on a specific group of persons with disabilities. While some pilot projects have attempted to include a diverse range of participants, the diversity of the disability community requires a response to a very broad range of support needs and specific groups may be in the best position to define those support needs. Furthermore, persons with a high level of support needs, including those with severe cognitive impairments, non-verbal communication and/or complex needs, are usually excluded. In that regard, providing access to a broad range of support arrangements seems better than developing a single model of supported decision-making. A "one size fits all" approach to supported decision-making is ineffective and discriminatory. States should take steps to ensure that all persons with disabilities are provided with the opportunity to access supported decision-making measures.

56. The nature of the relationship between the individual receiving support and those providing it varies significantly across practices. Some schemes rely on "trusted persons" for the provision of support, frequently family members, friends or peers who have a pre-existing relationship of personal knowledge and trust with the individual concerned. However, in many supported decision-making mechanisms, the supporters do not have a previously existing relationship with the individual receiving support, but are individuals and/or professionals who have been trained to provide support. Some schemes also utilize a mixed approach, operationalized through support networks that are facilitated by a trained individual but populated with trusted persons.

57. While having a relationship of trust can be conducive to a better understanding of the will and preference of the individual and facilitate the relationship between the individual and supporters, overreliance on persons who have existing relationships can also be problematic. Many people may not have a social network, may have experienced abuse and manipulation by relatives, or just do not want to be supported by relatives, friends or peers. Certain programmes have proved that individuals can build relationships of trust with volunteers and/or paid workers, especially when appropriate training and guidance is

[39] For example, Argentina, Australia, Bulgaria, Canada, Colombia, Czechia, Hungary, India, Ireland, Israel, Kenya, Latvia, Peru, Sweden, United Kingdom, United Republic of Tanzania and United States.

available.[31] In that regard, legislation should be flexible enough to respond to this diversity and should not prescribe one form of support over others.

58. While the majority of supported decision-making mechanisms outlined in legislation include some kind of formality (such as a signed agreement or a court order), there is no clear consensus among pilot projects and programmes on the benefits of operating under a formal arrangement. Some projects have identified many positive outcomes from the inclusion of a written agreement between individuals and their supporters, such as recognizing the autonomy and self-determination of the individual, tailoring and clarifying the scope of the support, making the supporter accountable and challenging community attitudes towards supported decision-making. Procedural safeguards can also be included into formalized support arrangements. However, some programmes intentionally exclude signed agreements, due to concerns about undermining the relationship of trust, as well as the informal nature of support.[32] Legal frameworks should therefore be flexible enough to recognize both informal and formal support arrangements and avoid overregulation.

59. The majority of supported decision-making practices include a component for training supporters to ensure respect for the will and preferences of individuals and avoid paternalistic attitudes, low expectations and substitute decision-making. Programmes with good practices on training typically involve supporters receiving initial comprehensive training and continuous training, including one-on-one coaching and problem-solving sessions.[33] Topics vary, including basic training on supported decision-making, person-centred approaches, strategies for supported decision-making and human rights. For example, peer support groups in Kenya receive training on human rights, including the rights-based approach to disability. It is important to ensure that clear and effective resources and training on supported decision-making are available and easily accessible for anyone providing or receiving support.

60. Community involvement has been demonstrated to contribute significantly to the success of supported decision-making. Providing support to make decisions is only helpful as long as others recognize those decisions. Community involvement is necessary to address structural factors that can hinder or violate the exercise of legal capacity of persons with disabilities, such as stigma, discrimination and institutionalization. In that regard, many supported decision-making initiatives have considered training for the authorities and for service providers, including judges, notaries and medical personnel, among others.

61. Communities also play a role in developing support alternatives, such as support networks or peer and self-support groups, as well as helping people to access existing support networks, particularly persons with a high level of support needs and older persons with disabilities, who may lack other sources of support. Indeed, community-based approaches for the provision of support constitute an effective strategy to ensure that responses consider geographical, social, economic and cultural issues (see A/HRC/34/58, para. 53). According to article 19 of the Convention, legislation must ensure a community-based approach in the provision of supported decision-making and facilitate the flourishing of social networks that ensure the individual autonomy and self-determination of persons with disabilities.

62. Supported decision-making initiatives use a broad range of safeguards, including adherence to the will and preferences of the individual concerned, express recognition of his or her right to withdraw from any arrangement, the establishment of time limits and periodic reviews of arrangements, coaching sessions and dispute-solving and monitoring mechanisms. In many projects, having multiple supporters was identified as a safeguard.

[31] See Brenda Burgen, "Reflections on the Victorian Office of the Public Advocate supported decision-making pilot project", *Research and Practice in Intellectual and Developmental Disabilities*, vol. 3, No. 2 (2016).

[32] See WestWood Spice, "My life, my decision: an independent evaluation of the supported decision making pilot", New South Wales Government Department of Community and Family Services (2015).

[33] See Burchist, "Supported decision-making service for persons with disabilities: Service model", schedule C (2017).

since it ensures that different points of view are present, reducing the risk of undue influence. In relation to monitoring mechanisms, many existing formalized schemes turn to a third party or independent person, who periodically contacts both the persons receiving and providing support to enquire about how support is provided. That informal type of monitoring is promising, as it avoids bureaucratization. When regulating safeguards, policymakers should strike a delicate balance between ensuring respect for the will and preferences of individuals and protecting them from abuse and undue influence, and ensuring that their lives and choices are not overregulated.

V. The way forward

A. Law reform

63. States must take immediate measures to reform their legal frameworks in order to ensure or restore the right to legal capacity of all persons with disabilities. It is important that legislation expressly recognize that persons with disabilities have the capacity to both hold and act upon rights and duties. Legislation must also recognize the right to access support for the exercise of legal capacity, if desired, and ensure that support arrangements are available, accessible, adequate and affordable. States must establish an enabling legal framework that facilitates the creation and implementation of various supported decision-making schemes, including the provision of financial and technical assistance to civil society organizations for that purpose. All substitute decision-making regimes must be repealed.

64. States must ensure an appropriate framework of safeguards to ensure respect for the rights, will and preferences of individuals in the provision of support and protect them from conflicts of interest, undue influence and abuses. When discussing crisis or emergency situations, States must adhere to the principles and rights recognized in the Convention. In particular, States must refrain from establishing exceptions to the full enjoyment of the right to legal capacity of persons with disabilities at all times and from creating new apparently disability-neutral responses that will disproportionately and adversely impact on persons with disabilities.[39]

65. States should initiate a comprehensive law review process and make changes in their legal systems to fully implement the right to legal capacity of persons with disabilities. The review must be comprehensive and encompass different areas of law, including family, criminal, mental health and tort and contractual law. The concerns of third parties, such as those regarding the duty of care, liability and the security of transactions, must be addressed in the light of the Convention. States must be aware that many experts working in the area of legal capacity are not familiar with the standards of the Convention and may thus require prior information and training. The law review process should include persons from different groups and sectors, including persons with disabilities themselves and those providing support in practice.

B. Policy development

66. States should consider establishing a comprehensive system to coordinate the effective access to supported decision-making of persons with disabilities. Such a system must adopt a human rights-based approach, take into account equality between men and women and the rights of the most disadvantaged and marginalized groups, and respond to the diversity of support needs of persons with disabilities, including older persons and those with a high level of support needs (see A/HRC/34/58, para. 58).

67. States must consider the implementation of pilot projects on supported decision-making, as part of their obligation to provide persons with disabilities with access to

[39] See Tina Minkowitz, "CRPD and transformative equality", *International Journal of Law in Context*, vol. 13, No. 1 (March 2017).

support for exercising their legal capacity. Demonstrations can provide legislators, policymakers and the wider community with valuable information about the functioning, cost and value of supported decision-making, thus contributing to a better legal and policy design.

68. Pilot initiatives should be implemented in collaboration with civil society organizations, particularly organizations of persons with disabilities who represent the full range of potential support users, including persons with intellectual disabilities, persons with psychosocial disabilities, persons with dementia, autistic persons and persons with brain injuries. That is in order to benefit from the outreach capacity of organizations of persons with disabilities, their knowledge of the local context and their mobilization and advocacy capacity (see A/HRC/34/58, para. 64). Supported decision-making experiences can also benefit from involving a broad range of local stakeholders, including authorities and service providers. Evaluation should be considered during programme design, including qualitative data that incorporates the perspectives of participants.

C. Research

69. States should undertake or promote research in relation to legal capacity and supported decision-making. Research can offer legislators and policymakers valuable information and possible lines of action to guarantee the right to legal capacity and to implement supported decision-making. There is a need for more quantitative and qualitative data on the current use of different forms of substitute decision-making to understand the extent and impact of that human rights violation, including involuntary commitment to a mental health facility and forced treatment. Similarly, despite the increasing implementation of supported decision-making schemes, there is still a clear need for better quality data to inform subsequent initiatives and policy design. Research on supported decision-making has predominately concentrated on formalized forms of support, with little attention paid to other informal forms of support in decision-making, such as natural support networks or the support provided in the framework of peer support groups. There is a need to understand how all those forms of support operate and how they relate and contribute to the exercise of legal capacity of persons with disabilities.

70. Importantly, research on supported decision-making should respond to the rights of persons with disabilities and include the perspective of the disability community. In line with article 4 (1) (d) of the Convention, States should refrain from funding or engaging in any research project that is inconsistent with the right to legal capacity of persons with disabilities, as enshrined in article 12. Research should, wherever possible, be led by researchers with disabilities, be participatory and include the views of persons with disabilities and their organizations in all phases. Outcomes should be published in accessible formats, including easy-to-read versions.

D. Access to justice

71. While the recognition of the right to legal capacity is fundamental to guaranteeing access to justice, it is also essential for the protection and restoration of legal capacity.[25] As required by article 13 of the Convention, States must take appropriate measures to ensure effective access to justice for persons with disabilities on an equal basis with others and promote appropriate training for those working in the field of administration of justice. States should also take all appropriate measures to ensure that persons with disabilities have access to procedural and age-appropriate accommodations, including supported decision-making, in all legal proceedings before, during and after trial.

72. States must ensure that all persons under substitute decision-making regimes have access to an effective remedy and consider a moratorium on new applications. They must also guarantee that all persons with disabilities who have experienced any form of

[25] See Committee on the Rights of Persons with Disabilities, general comment No. 1, para. 38.

exploitation, violence or abuse in the context of substituted or supported decision-making regimes, including arbitrary detention or violations of personal integrity pursuant to mental health legislation, have access to justice and effective remedies. Those remedies should include adequate redress and reparations, including restitution, compensation, satisfaction and guarantees of non-repetition, as appropriate (see A/HRC/34/58, para. 74). National human rights institutions and independent mechanisms for the promotion, protection and monitoring of the implementation of the Convention should be mandated to carry out inquiries and investigations in relation to the enjoyment of the right to legal capacity of persons with disabilities and provide assistance to persons with disabilities in accessing legal remedies.

73. Litigation can play an important role in the reform of legislation on legal capacity. It can have an impact beyond those directly involved in a particular case, leading to new judicial criteria and changes in the law. In monist countries where treaties are immediately incorporated into domestic law once they have entered into force, litigation has the added value of ensuring the direct application of article 12 of the Convention, thus creating a shift in case law. Indeed, in many countries courts are already applying the standards of the Convention, challenging existing legislation that denies persons with disabilities the full recognition of legal capacity.[76]

E. Participation and collaboration

74. Article 4 (3) of the Convention explicitly requires States to consult closely with and actively involve persons with disabilities, including children with disabilities, in the development and implementation of legislation and policies concerning issues relating to them. States should closely consult with and actively involve persons with disabilities and their representative organizations in the process of legal harmonization regarding legal capacity. While the legislative process may vary from country to country, legislatures should guarantee the participation of persons with disabilities throughout the entire process, inclusive of deliberative assemblies or chambers that can debate and vote on law proposals. In many countries, citizens have the right to propose legislative initiatives, referendums and petitions without the endorsement of political parties or the State authorities. States must ensure that the procedures of direct democracy are fully accessible for persons with disabilities.

75. Persons with disabilities and their representative organizations must also participate in all decision-making processes related to the design, implementation, monitoring and evaluation of support services and arrangements. The Special Rapporteur's thematic study on the right of persons with disabilities to participate in decision-making provides specific guidance in that regard (A/HRC/31/62).

F. Capacity-building

76. States must complement law reform efforts with training for State authorities, public officials, service providers, the private sector, persons with disabilities, families and other key actors. Capacity-building on the Convention is indispensable to ensure the adequate implementation of the right to legal capacity of persons with disabilities. Training should also address the intersecting forms of discrimination with regard to legal capacity that affects persons with disabilities and the forms of prejudice and barriers encountered by specific groups of persons with disabilities, as well as how to promote and deliver supported decision-making.

77. States must promote appropriate training for those working as notaries, since they play an important role, particularly in civil law countries, in concluding and formalizing legal transactions, such as contracts, wills, and powers of attorney. In doing so, notaries make assessments of the capacity of individuals entering into legal relationships. It is

[76] For example, Argentina, Colombia, Georgia, Kenya, Latvia, Peru and the United States.

therefore important that notaries understand the recognition of universal legal capacity and the support paradigm brought forward by the Convention, in order to ensure that their work does not translate into a de facto restriction of legal capacity. They must also receive appropriate training in the provision of accessibility measures and reasonable accommodation.

78. The role of academia in promoting the right to legal capacity of persons with disabilities is critical, particularly in education, research and innovation. Universities should review their curricula to ensure that the education they offer adequately reflects the innovations of the Convention in relation to the legal capacity of persons with disabilities. They can also support the implementation and evaluation of supported decision-making initiatives. The direct involvement of persons with disabilities with and within academia, and the development and strengthening of critical studies based on the perspectives of persons with disabilities, can strengthen the capacity of universities to identify challenges and propose better solutions.

G. Awareness-raising

79. A cultural change in how persons with disabilities are perceived by their communities is essential for ensuring that the decisions of persons with disabilities are respected. States must adopt immediate, effective and appropriate measures to raise awareness throughout society, including at the family level, regarding the abilities and rights of persons with disabilities. States should also take measures to combat stereotypes, negative attitudes and harmful and involuntary practices against persons with disabilities in all areas of life, and promote the support paradigm in decision-making. Persons with disabilities must not be seen as objects of care, but rather as rights holders in the same way as every member of society (see A/71/314, para. 74).

H. Resource mobilization

80. States have an obligation to mobilize resources to their maximum availability to ensure access to the right to legal capacity, including funding supported decision-making initiatives, research, training and awareness-raising campaigns. States must also refrain from funding any act or practice that is inconsistent with the right to legal capacity of persons with disabilities and ensure that the public authorities, service providers and other stakeholders act in conformity with it. Retrogressive measures that affect access to support for persons with disabilities in different areas of life, such as cuts or reductions in subsidies for community support services, in-home services and personal assistance, can also impact the exercise of the right to legal capacity.

81. The United Nations, including all its programmes, funds and specialized agencies, should increase the awareness and expertise of its staff in relation to the right to legal capacity of persons with disabilities. International cooperation should also consider increasing funding for the design and development of supported decision-making initiatives, ensuring that those interventions are consistent with the human rights of persons with disabilities.

VI. Conclusions and recommendations

82. **Throughout history, legal capacity has been denied to many persons with disabilities, who have therefore been deprived of the exercise of their rights. While the practice has been widely accepted and viewed as necessary to protect both the individuals concerned and society, it has proved to be wrong. Denial of legal capacity takes away people's control over their everyday lives and significantly reduces their opportunities to participate in society. Furthermore, it has legitimized and facilitated the continuation of harmful practices, such as coercion, institutionalization and sterilization, prompting the ultimate objectification of persons with disabilities. Against that background, the Convention on the Rights of Persons with Disabilities**

reaffirms the universality, indivisibility, interdependence and interrelatedness of all human rights and fundamental freedoms, and recalls the role of society in ensuring their full enjoyment. States have an obligation to guarantee the full enjoyment of human rights for all persons with disabilities. The recognition of full legal capacity and supported decision-making are necessary steps for making rights a reality, providing persons with disabilities with the freedom and opportunity to live the lives they value.

83. States must pay special attention to the right to legal capacity of persons with disabilities and champion law and policy reforms towards its full implementation. As the present report illustrates, the standards introduced by the Convention are being progressively implemented at the international, regional and national levels. The review of substituted decision-making regimes and the implementation of different forms of supported decision-making in many jurisdictions reveal a gradual but steady paradigm shift. There is a broad range of measures that States can implement to respect and ensure the right to legal capacity of persons with disabilities. However, States and their leaders need to systematize those lessons and turn them into systemic, comprehensive and sustainable policy responses.

84. The Special Rapporteur makes the following recommendations to States with the aim of assisting them in developing and implementing reforms towards the full implementation of the right of legal capacity:

(a) Recognize, in domestic legislation, the right of persons with disabilities to legal capacity on an equal basis with others in all aspects of life, and provide them with access to the support they may require in exercising their legal capacity;

(b) Conduct a comprehensive law review process to abolish or revoke all laws and regulations that directly or indirectly restrict the legal capacity of persons with disabilities and/or allow for substituted decision-making;

(c) Adopt an enabling policy framework to ensure the effective access of persons with disabilities to appropriate supported decision-making arrangements, by (a) establishing a comprehensive system to coordinate access to supported decision-making arrangements across the territory, including in rural and remote areas; (b) promoting the establishment and sustained operation of community-based supported decision-making alternatives, including the allocation of resources; (c) implementing or promoting pilot projects and demonstration experiences; and (d) undertaking or promoting research on supported decision-making;

(d) Introduce safeguards in the provision of support related to the exercise of legal capacity to guarantee respect for a person's will and preferences at all times;

(e) Guarantee access to effective remedies to all persons with disabilities currently under substitute decision-making regimes and take immediate action to restore their legal capacity, including the adoption of a moratorium on new applications;

(f) Promote and provide training on the right to legal capacity of persons with disabilities for State authorities, judges, notaries, service providers, persons with disabilities, their families and other relevant actors;

(g) Actively involve and consult with persons with disabilities and their representative organizations in all decision-making processes related to the implementation of the right to legal capacity of persons with disabilities, including law reform, policy development and research;

(h) Progressively increase the allocation of funds to ensure access to supported decision-making and refrain from adopting any retrogressive measures that directly or indirectly affect the access of persons with disabilities to support;

(i) Encourage international cooperation actors, including non-profit organizations, to fund and carry out research, provide technical assistance on legal capacity law reform and supported decision-making, and refrain from implementing

or supporting projects that contravene the Convention on the Rights of Persons with Disabilities.

85. **The Special Rapporteur also recommends that the United Nations system, including all its programmes, funds and specialized agencies, enhance its capacities and adequately consider the right to legal capacity of persons with disabilities in all its work, including when supporting the legislative and policy reforms of States.**

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Report of the Special Rapporteur on the rights of persons with disabilities on her visit to the Democratic People's Republic of Korea

Note by the Secretariat

The Secretariat has the honour to transmit to the Human Rights Council the report of the Special Rapporteur on the rights of persons with disabilities, Catalina Devandas Aguilar, on her mission to the Democratic People's Republic of Korea from 3 to 8 May 2017. In her report, the Special Rapporteur explores issues relating to her mandate in the light of the Convention on the Rights of Persons with Disabilities and other international human rights instruments. On the basis of the information gathered prior to, during and after the visit, she reflects on the situation of persons with disabilities in the Democratic People's Republic of Korea. She emphasizes gaps, shortcomings and areas where technical cooperation would be beneficial. Her recommendations aim to advance the rights of persons with disabilities in the country.

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Report of the Special Rapporteur on the rights of persons with disabilities on her visit to the Democratic People's Republic of Korea*

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* Circulated in the language of submission only.

I. Introduction

A. Programme of the visit

1. Following a recommendation by the Special Rapporteur on the situation of human rights in the Democratic People's Republic of Korea (see A/70/362, para. 22), the Special Rapporteur on the rights of persons with disabilities requested a visit to the Democratic People's Republic of Korea. The visit took place from 3 to 8 May 2017 with a view to learning about the situation of persons with disabilities, the existing opportunities, challenges and shortcomings in the recognition of their rights and making recommendations to advance the implementation of the Convention on the Rights of Persons with Disabilities. The visit was the first ever to the country by a special procedures mandate holder of the Human Rights Council.

2. The Special Rapporteur visited Pyongyang and the town of Pongchon in South Hwanghae province. At national level, she met with senior government officials, including the Ambassador for Human Rights of the Ministry of Foreign Affairs, the Division Director of Human Rights and Humanitarian Issues of the Ministry of Foreign Affairs, the Minister of Public Health, the Division Director of the Legislative Department of the Presidium of the Supreme People's Assembly, the Division Director of the Education Commission and the Chairman of the Korean Federation for the Protection of the Disabled. At the provincial level, she met with the Director of the Education Department of the People's Committee of South Hwanghae province and a member of the provincial committee of the Korean Federation for the Protection of the Disabled.

3. The Special Rapporteur also met with representatives of the Deaf Association of Korea, the Blind Association of Korea, a number of persons with other impairments, the United Nations country team, the diplomatic community, humanitarian agencies and international cooperation actors.

4. In Pyongyang, she visited the Okryu children's hospital, the Munsu Functional Rehabilitation Centre, the Korean Rehabilitation Centre for Children with Disabilities, the Sci-Tech Complex and the Pyongyang primary boarding school. She also attended the closing ceremony of an amateur table tennis tournament for people with and without disabilities and a performance by the Korean Art Association of the Disabled. In Pongchon, she visited a special school for the blind. On 9 May 2017, she met with representatives of the Korean Foundation for the Disabled and Orphans in Beijing.

5. Although most requests for meetings and visits to places of interest to her mandate were accepted, the Special Rapporteur regretted that her request to meet with the Central Court, the Minister of Labour, the Minister of City Management, the Ministry of State Construction Control, the Central Bureau of Statistics and a visit to a mental health facility were not accommodated. She also regretted that she could only meet with a limited number of persons with disabilities and that there was no possibility to hold discussions with them in private.

6. The Special Rapporteur expressed her appreciation to the Government of the Democratic People's Republic of Korea for the cooperation extended to her prior, during and after the visit, and to the Korean Federation for the Protection of the Disabled and its staff in particular. She also wishes to thank especially all the persons with disabilities with whom she was able to interact. She is grateful to the United Nations Resident Coordinator and his office for the valuable assistance provided in support of the visit.

B. Context

7. The Democratic People's Republic of Korea is a socialist State driven by the Juche ideology, which emphasizes the principles of political and economic independence, self-reliance and self-defence. According to article 8 of the Socialist Constitution, the country follows a "people-centred system whereby the working people are the masters of

everything and everything in society serves them". The country is administratively divided into nine provinces and three directly controlled cities. The industrial sector is one of the major components of the national economy. Agriculture is the other foundation of the economy and the State is the owner of all land and productive assets. The State manages and allocates food, housing, work, heath care, education and other services to the population.

8. The country is not ranked in the Human Development Index and there is only limited information available on the components of the index.[1] Data on poverty, household income or expenditure is not collected and there is no nationally defined poverty line. According to the United Nations Children's Fund (UNICEF), in 2013 the gross domestic product (GDP) per capita was estimated at $1,013.[2] In 2013, the proportion of State budgetary expenditure on public health and education were respectively 6.4 per cent and 8.4 per cent of GDP (see CRC/C/PRK/5, annex, table 2).[3]

9. The 2008 census indicated that the population stood at 24 million, with an average annual growth rate of 0.85 per cent. Of that population, 48.7 per cent were men and 51.3 per cent women. In terms of distribution, 60.6 per cent were residing in urban areas and 39.4 per cent in rural areas.[4] Current estimates indicate a total population of 24.9 million.[5]

10. With respect to data on persons with disabilities, the 2008 census, which included part of the short set of questions of the Washington Group on Disability Statistics, indicated that 8.1 per cent of the population aged over 5 had a visual, hearing, physical or intellectual disability. The prevalence of disability in women was much higher (62 per cent) than in men (32 per cent). The disability sample survey conducted in 2014 in four provinces estimated a disability rate of 6.2 per cent of the overall population (approximately 1.5 million), with a prevalence of 55.1 per cent in women and 44.9 per cent in men.[6]

11. Since the mid-1990s, the country's humanitarian situation has been exacerbated by recurring natural disasters, leading to widespread and chronic shortages of food, water and sanitation services, as well as protracted food insecurity and undernutrition for a majority of the population. Estimates indicate that some 5.6 million people were affected by natural disasters between 2004 and 2015, and that today some 18 million people are affected by food insecurity, malnutrition and lack of access to basic services.[7] At the global level, international trade and investments are restricted owing to Security Council sanctions imposed on the country since 2006 for its nuclear and missile tests. While the international sanctions clearly exempt humanitarian and other similar activities, they have directly contributed to reluctance among donors to fund projects in the country.

12. Despite the sanctions, the country has continued to develop its nuclear and ballistic technology and to conduct nuclear tests, which has resulted in increased political and military tensions and a threat to peace and security. In recent months, the Security Council has adopted several resolutions condemning the country's pursuit of ballistic and nuclear weapons and has strengthened its sanctions against the country. That has led to the country becoming increasingly isolated, which directly affects persons with disabilities.

13. The country has very little access to information, technology, skills and knowledge of new methodologies in the area of disability. While travelling outside Pyongyang, the

[1] See http://hdr.undp.org/en/countries/profiles/PRK.

[2] See UNICEF, "Situation analysis of children and women in the Democratic People's Republic of Korea - 2017" (2016), p. 17.

[3] According to UNdata, in 2014 GDP amounted to $17.4 million, see http://data.un.org/CountryProfile.aspx?crName=Democratic%20People%27s%20Republic%20of%20Korea.

[4] Central Bureau of Statistics, Population Census 2008 (2008) available at https://unstats.un.org/unsd/demographic/sources/census/wphc/North_Korea/Final%20national%20census%20report.pdf.

[5] Humanitarian country team and partners, "DPR Korea needs and priorities 2017", p. 1.

[6] Korean Federation for the Protection of the Disabled, "*Disability sample survey 2014. DPRK*" (2015).

[7] Humanitarian country team and partners, "DPR Korea needs and priorities", pp. 3 and 5.

Special Rapporteur noted the stark disparity in the availability of services and the enjoyment of rights by persons with disabilities between the capital and rural areas. The lack of accessibility and essential services outside Pyongyang disproportionally affect persons with disabilities in a situation of poverty. She noted that any travel within the country is strictly regulated through the requirement of advance travel clearance and checkpoints on the main roads. She was also informed that no travel was authorized to certain counties and to Jagang province. This generalized denial of freedom of movement within the country disproportionally affects persons with disabilities, who may be in urgent need of accessing health care and other specialized services in Pyongyang and other localities.

II. Situational analysis and achievements

A. Legal framework

14. At the international level, the Democratic People's Republic of Korea is a State party to the International Covenant on Civil and Political Rights,[3] the International Covenant on Economic, Social and Cultural Rights, the Convention on the Rights of the Child and its Optional Protocol on the sale of children, child prostitution and child pornography and the Convention on the Elimination of all Forms of Discrimination against Women. In 2016, the Government ratified the Convention on the Rights of Persons with Disabilities and the Marrakesh Treaty to Facilitate Access to Published Works for Persons Who Are Blind, Visually Impaired or Otherwise Print Disabled. The country is not a party to the Optional Protocol to the Convention on the Rights of Persons with Disabilities and the authorities there have expressed their intention not to ratify it for the time being.

15. In 2016, the country submitted its fifth State party report to the Committee on the Rights of the Child and its combined second to fourth report to the Committee on the Elimination of Discrimination against Women, which were reviewed in September and November 2017 respectively. Both reports included sections on the rights of persons with disabilities. The State is however overdue to present its fourth reports to the Human Rights Committee and the Committee on Economic, Social and Cultural Rights. In 2014, it underwent its second universal periodic review and accepted approximately two thirds of the recommendations, which included disability-related recommendations. In 2013, the Human Rights Council established a Commission of Inquiry into human rights in the Democratic People's Republic of Korea, which is not recognized by the country. The final report of the Commission contains several paragraphs related to persons with disabilities (A/HRC/25/63).

16. The Democratic People's Republic of Korea continues to reject Human Rights Council and Security Council resolutions on the human rights situation in the country and does not therefore recognize the mandate of the Special Rapporteur on the situation of human rights in the Democratic People's Republic of Korea. However, State officials have indicated that the country is open for dialogue and cooperation with other thematic mandate holders. The Special Rapporteur hopes that the State will reconsider its cooperation with the Special Rapporteur on the situation of human rights in the Democratic People's Republic of Korea and reminds the State of its obligations stemming from the International Covenant on Civil and Political Rights, to which it is still a party. She encourages the State

[3] On 25 August 1997, the Secretary-General received a notification of withdrawal from the Covenant from the Government, dated 23 August 1997. As the Covenant does not contain a withdrawal provision, on 23 September 1997, the Secretariat forwarded an aide-memoire to the Government explaining the legal position arising from its notification. As elaborated in the aide-memoire, the Secretary-General is of the opinion that a withdrawal from the Covenant would not appear possible unless all States parties to the Covenant agree to such a withdrawal. The notification of withdrawal and the aide-memoire were duly circulated to all States parties under cover of C.N.467.1997.TREATIES-10 of 12 November 1997.

to accept requests for country visits from other thematic special procedure mandate holders and to grant them unconditional freedom of movement in the country.

17. The domestic normative framework of the Democratic People's Republic of Korea provides protection and assistance to persons with disabilities, including specific references to persons with disabilities contained in the Constitution. For example, article 72 guarantees free medical care and material assistance to all persons who are no longer able to work because of old age, illness or disability. However, other articles contravene the Convention on the Rights of Persons with Disabilities, as illustrated in paragraphs 26–28 below.

18. The law on the protection of persons with disabilities, adopted in 2003 and amended in 2013, formally provides legal rights to persons with disabilities, primarily in the areas of rehabilitation, education, work and cultural life. It also establishes a central coordination mechanism for the protection of the rights of persons with disabilities (art. 45), as required by article 33 (1) of the Convention. The amended law brought the definition of disability (art. 2) into line with the Convention and introduced new provisions, such as the establishment of research centres to collect data on persons with disabilities (art. 51), measures to improve the accessibility of public infrastructure and services (arts. 47 and 48), or the establishment of a foundation for the support of persons with disabilities (art. 52). Nonetheless, the law only incorporates certain provisions of the Convention, while excluding other important ones, for example those relating to the right to equal recognition before the law, liberty of movement, living independently and being included in the community, freedom of opinion and expression, and women with disabilities. There are also provisions of the law that do not conform to the Convention, as discussed in paragraphs 26–28 below.

19. The Government has also adopted or amended other general legislation that has introduced positive changes for persons with disabilities. They include the law on the protection and promotion of the rights of the child, which states that children with disabilities have equal rights with others to receive education and medical care; the law on public health which provides for free medical care to persons with disabilities; the socialist labour law which grants subsidies and disability pensions to workers with disabilities; and the law on disaster prevention, rescue and recovery, which gives priority to children, women and persons with disabilities in the delivery of relief goods.

20. The Special Rapporteur was informed of the adoption of implementing regulations to enforce State legislation, such as the regulations on job placement, the regulations for schools for the blind and the deaf, the regulations on social insurance and social security, or the regulations on medical assessments of the ability to work, but did not have access to them.

II. Institutional and policy frameworks

21. The Special Rapporteur acknowledges the efforts made to address the needs of persons with disabilities. According to the information received, in the past 15 years the Government has undertaken a number of initiatives that have the potential to enhance the situation of this population group.

22. She appreciates the establishment in 2016 of the Central Committee for the Protection of Persons with Disabilities within the Cabinet, which serves as the national coordination mechanism, as required by article 33 (1) of the Convention on the Rights of Persons with Disabilities.

23. The Korean Federation for the Protection of the Disabled, an institution under the Cabinet which provides direction for the effective implementation of legislation and policy on the protection of persons with disabilities, has also made efforts to advance the disability agenda within the Government and to serve as the technical focal point in line with article 33 (1) of the Convention. The Special Rapporteur acknowledges the efforts that are under way to strengthen the Federation through the recruitment of personnel and through skills training. The Federation has approximately 20 full-time staff based in Pyongyang, including 4 persons with disabilities, and a representative in five provinces, where it has

established provincial branches. The Special Rapporteur was informed that the Federation was in the process of recruiting an additional 20–25 staff to serve as focal points on disability, who will be located within line ministries. She hopes that those focal points will include persons with disabilities.

24. During her visit, the Special Rapporteur was told that the Federation was also in the process of developing a strategic national action plan for the protection of persons with disabilities for the next decade, to be finalized by the end of 2017. The plan is expected to cover actions in priority areas, such as rehabilitation, inclusive education, work opportunities for persons with disabilities, accessibility of the physical environment across the country, increased social awareness on disability and strengthened collaboration with the international community. Furthermore, the Federation was developing substrategies in the areas of rehabilitation, vocational training and education.

25. The Special Rapporteur has not received any information about other general State policies and whether these are inclusive of persons with disabilities.

C. Outstanding legal issues

1. Legal and policy harmonization

26. The Special Rapporteur only had access to the legislation made available to her by the State, despite her request for additional legislation.[*] She expressed concern about the existence of legislation that is discriminatory towards persons with disabilities. She noted for instance the use of pejorative language to refer to persons with disabilities in several official documents, such as the terms "dumb" (for example, articles 172 and 229 of the law on criminal procedures, article 49 of the law on civil procedures, article 30 of the law on the protection and promotion of the rights of the child and the fifth periodic report of the State party to the Committee on the Rights of the Child); "incapable" and "cripples" (mentioned in article 78 of the amended socialist labour law of 2015), "invalids" (article 13 of the public health law), "partially or totally incompetent" (article 49 of the civil procedures law), or "insane" (article 66 of the Socialist Constitution).

27. She also notes with concern the discriminatory provisions against persons with intellectual and psychosocial disabilities contained in article 66 of the Socialist Constitution, article 50 of the law on the protection of persons with disabilities, article 49 of the law on the protection and promotion of women's rights, article 45 of the law on the protection and promotion of the rights of the child and articles 40 and 41 of the family law, which are not compliant with articles 12, 23 and 29 of the Convention on the Rights of Persons with Disabilities. They provide for the appointment and regulation of a guardianship system for persons considered unable to exercise their legal capacity on the grounds of their disability and deny them the right to vote and be elected, to act as a guardian of a child, or to adopt a child, with no recourse for appeal and review.

28. To complete the process of legal harmonization in accordance with article 4 of the Convention, the legislative authorities should undertake a comprehensive review of the normative framework and repeal or amend all provisions that are contrary to the Convention.

2. Implementation and safeguard monitoring of the Convention on the Rights of Persons with Disabilities

29. According to the information received, the Korean Federation for the Protection of the Disabled is the focal point within the Government for matters relating to the implementation of the Convention, while the Central Committee for the Protection of

[*] The Special Rapporteur requested but did not have access to the law on general secondary education (2011), the law on higher education (2011), the decree on the enforcement of universal 12-year compulsory education (2012), the social security law (2012) or the law on the protection of the elderly (2007).

Persons with Disabilities within the Cabinet was created to function as the national coordination mechanism, both in accordance with article 33 (1) of the Convention.

30. Since the ratification of the Convention, the Korean Federation for the Protection of the Disabled has started a process of recruitment of focal points to advise line Ministries on disability mainstreaming. The Federation is also in charge of drafting the national action plan for the protection of persons with disabilities, which needs to be adopted by the Central Committee for the Protection of Persons with Disabilities.

31. The Central Committee for the Protection of Persons with Disabilities is chaired by the Vice-Premier, and composed of representatives of the Education Commission, the Ministry of Labour, the Ministry of Public Health and other line ministries, the Korean Federation for the Protection of the Disabled and representatives of the Deaf Association of Korea and of the Blind Association of Korea. The Special Rapporteur was informed that the Ministry of Public Security would also become a member of the Committee to guarantee the inclusion of disability-related issues in the area of deprivation of liberty, which is a welcome development. Furthermore, the Special Rapporteur recommended that the Ministry of City Management and the Ministry of State Construction Control be included as members.

32. The Special Rapporteur urges the relevant authorities to promptly submit the strategic national action plan for the protection of persons with disabilities for approval. The plan should include time-bound benchmarks for implementation at provincial, district and county levels, along with the corresponding budgetary measures, to ensure that all persons with disabilities across the country benefit equally from its implementation.

33. The Special Rapporteur emphasizes the need to ensure coherence and coordination between the focal points being recruited by the Federation, since it is important that they are given a clear mandate and terms of reference and full-time responsibility, and are equipped with adequate resources and training to perform their tasks effectively.

34. The Special Rapporteur also observes that the Democratic People's Republic of Korea has yet to set up an independent mechanism, compliant with the principles relating to the status of national institutions for the promotion and protection of human rights (Paris Principles), to monitor the implementation of the Convention, as required by article 33 (2), and encourages the Government to do so as soon as possible.

III. Challenges and opportunities identified in the Democratic People's Republic of Korea

35. The Special Rapporteur was able to obtain only limited information on the situation of persons with disabilities. Furthermore, she notes that the majority of the information received from external sources relating to persons with disabilities in the country is outdated. Her report therefore relies primarily on information gathered during the visit.

A. Data collection

36. There is very limited data, across all sectors, disaggregated by disability and other parameters, including age, gender and geographic location. Nevertheless, it is a positive indication that the 2008 census included for the first time questions on disability, and that a disability sample survey was conducted in four provinces (South Hamgyong, Kangwon and North and South Pyongan) in 2014. The survey results were further disaggregated by age, sex, type of disability, marital status, labour activity and education level. The Central Bureau of Statistics also conducted a socioeconomic, demographic and health survey in 2014 with the support of the United Nations Population Fund (UNFPA), which collected information on reduced mobility in older persons.

37. The Special Rapporteur was pleased to learn that the next population census in 2018 will include the whole set of questions of the Washington Group on Disability Statistics, and that the 2017 multiple indicator cluster survey to be conducted later in 2017 will

include the UNICEF-Washington Group module on child functioning, which will make it possible to disaggregate data by disability and age, and obtain internationally comparable data. She strongly encourages all relevant authorities to apply the methodology developed by the Washington Group on Disability Statistics in all future data-collection efforts.

38. According to the information received, the Government has a centralized disability management information system, which includes information provided by household doctors across the country. However, the Special Rapporteur was not given access to such administrative data. In addition, article 5 of the law on the protection of persons with disabilities provides that the State shall periodically survey the actual conditions of persons with disabilities and assess their degree of disability. Moreover, article 10 of the law tasks medical and other institutions to periodically identify and register persons with disabilities according to their type of disability.

B. Stigma and discrimination

39. During her visit, the Special Rapporteur observed the prevalence of the medical model of disability and that it permeated and influenced the way in which persons with disabilities were perceived and treated by society, despite the spirit of the amended law on the protection of persons with disabilities. She noted that the emphasis is still on "treating", "curing" and "rehabilitating" persons with disabilities.

40. The ideal of being healthy and strong is highly valued in the Democratic People's Republic of Korea, since each person is expected to defend the country and contribute to its development. Any sign of weakness is considered shameful and those who do not contribute to society are despised. In that context, persons with disabilities are easy targets of stigma and discrimination and are often neglected by their home communities and authorities. The Special Rapporteur was informed that families are reluctant to expose their relatives with disabilities in the community and that women and girls with disabilities, in particular, are ashamed to participate in local activities, owing to the strong stigma attached to impairment. Moreover, persons with disabilities with no opportunities to work are looked down upon, because they are not considered to be productive members of society.

41. The Special Rapporteur was told of an existing practice according to which young women will "sacrifice themselves" and volunteer to marry veterans with disabilities, as a way to recognize their contribution to the country, because otherwise, owing to their impairments, they will not find a spouse.

42. In general, persons with disabilities continue to be excluded and segregated. They receive specialized services in separate settings, depriving them of access to facilities and services on an equal basis with others. The Special Rapporteur notes that State efforts are focused primarily on deaf and blind persons and that all services are provided to them in a segregated manner; whereas the people she met explained that one of their main desires was to have access to the same level of services as everyone else. During her visit, she was informed of the challenges faced by wheelchair users, who had often been home-schooled owing to the lack of accessibility of their homes, and were advised to follow particular professional paths based on stereotypes about their impairments. The Special Rapporteur also saw one little person (a child with achondroplasia), a few autistic children and children with intellectual disabilities, all residing in specialized segregated settings, but she could not obtain information from them on their particular situation. She is greatly concerned about this segregated approach that perpetuates discrimination and stigma against persons with disabilities.

43. The Special Rapporteur received allegations that other persons with disabilities live in isolated special facilities, including little persons and persons with psychosocial disabilities, but could not verify the information. In fact, she did not meet anyone with psychosocial, multiple or severe disabilities. She is also greatly concerned about their situation and living conditions, as these groups often face the most aggravated forms of discrimination. However, their situation remains totally unknown to her, as the Government did not facilitate any meetings with such groups or visits to the facilities in which they reside.

44. The Special Rapporteur encourages the Government to combat stereotypes and prejudices against persons with disabilities. National media needs to be involved to change the perception of disability in society and portray a positive image of the diversity of persons with disabilities. In that regard, she welcomes the fact that the Korean Federation for the Protection of the Disabled is cooperating with the Korean Central News Agency and the Radio-TV Broadcasting Committee to develop media campaigns to change social perceptions about persons with disabilities. Efforts should promote the correct terminology when referring to persons with disabilities and discontinue the use of terms such as "sane", "healthy", "able-bodied" or "normal", which she heard repeatedly in various official meetings. While she welcomes the action taken by the Federation to raise awareness of the need to recognize the dignity of persons with disabilities, particularly in the fields of sport and the arts and through annual celebrations of national and international days of persons with disabilities, she encourages the Government to increase and expand these programmes to other areas too.

C. Accessibility

1. Access to the physical environment

45. During the visit, the Special Rapporteur observed that most of the infrastructure is not accessible to persons with disabilities, including new public buildings such as the Sci-Tech Complex built in 2015, Pyongyang International Airport (arrivals area) inaugurated in 2016 and Pyongyang primary boarding school, which was entirely refurbished in February 2017. Housing facilities are not accessible, environmental barriers and limited access to public transportation are major challenges that have an impact on the rights of persons with disabilities to live autonomously and to participate fully in all aspects of life.

46. The Special Rapporteur was informed that the National Construction Committee, under the Ministry of State Construction Control, has developed regulations on accessibility and that since May 2017, persons with disabilities who live in Pyongyang can use taxi services free of charge. However, she notes that the country is not using updated accessibility standards. She welcomes the request by the State for specific technical assistance in the area of international standards on accessibility and universal design and its interest in increasing information exchange with international partners in technical areas.

47. The Ministry of State Construction Control and its technical staff in charge of monitoring the construction and maintenance of public buildings should monitor the implementation of the regulations on accessibility for new construction and consider making an accessibility needs assessment of existing infrastructure to be refurbished across the country, including roads, schools, hospitals, workplaces, public administration offices, courts, police stations, museums and cultural facilities and other public places.

2. Access to information and communications

48. With regard to access to information and communications, the Special Rapporteur acknowledges several positive developments for deaf persons, including the recognition of Korean sign language as an official language since 2003, the existence of an association of sign language interpreters with deaf interpreters, the possibility for deaf persons to send free text messages and the provision of sign language interpreters during investigation and trials in accordance with articles 172 and 229 of the law on criminal procedures and article 12 of the law on civil procedures. There is also an initiative under discussion to grant them reduced fees on phone calls. At the Sci-Tech Complex, the Special Rapporteur visited the special e-reading room equipped with a virtual platform with sign language features to enable deaf persons to access information, as well as audio files and Braille keyboards for blind persons. However, she was informed that there was no captioning or sign language interpretation on the news or on any other television programme or mass media event. With respect to blind persons, she was informed that the use of screen readers was not available in the country and that the Kwangmyong Publishing House printed Braille documentation, although in insufficient numbers.

49. In relation to information and communications technology, the Korean Federation for the Protection of the Disabled is collaborating with the Pyongyang Information Centre, which is under the authority of the National Bureau of Information, to provide persons with disabilities with access to new technologies and systems, including access to distant learning through the local intranet system. Nonetheless, more efforts are needed to ensure full coverage and access to information and communications for the diversity of persons with disabilities across the country.

D. Participation

50. The Korean Federation for the Protection of the Disabled has been promoting the creation of affiliated associations of persons with disabilities at national, provincial and county level, and coordinates closely with them. These associations include for instance the Korean Association of Women with Disabilities (at the provincial level), the Korean Art Association of the Disabled, and the Korean Sports Association of the Disabled. Moreover, the representatives of the Association of the Deaf and the Association of the Blind participate in the meetings of the Central Committee for the Protection of Persons with Disabilities, which is a positive development. Nonetheless, representation on the Central Committee should be expanded to include persons with other types of impairments. The Federation coordinates monthly meetings of all associations of persons with disabilities.

51. More efforts are required to ensure that consultations are held and the diversity of persons with disabilities is represented in decision-making, including in rural and remote areas. While the Special Rapporteur welcomes the fact that associations of the deaf and of the blind are composed exclusively of persons with disabilities, she encouraged the Government to promote and support the establishment of independent self-managed associations representing all persons with disabilities, including little persons and those with physical, intellectual, developmental, psychosocial and multiple impairments, who are currently not represented by any of the existing associations.

52. The Government must take into consideration the views and opinions of persons with different impairments when devising public policies affecting persons with disabilities. To increase the participation of persons with disabilities, she calls on the State to promote an environment in which they can effectively and fully participate in the conduct of public affairs, and in which they can be invited to participate in policymaking and legislation processes affecting them. Moreover, the Government should encourage and support the designation of persons with disabilities in public functions and in the Supreme People's Assembly. The meaningful participation of women with disabilities should also be strengthened.

E. Education

53. According to official data from 2010 and 2013, there were over 28,000 nurseries, 14,312 kindergartens, 4,822 primary schools, 4,366 junior secondary schools, 4,328 senior secondary schools, 460 colleges and 302 universities in the country (see CEDAW/C/PRK/2-4, para. 100).[10] Additionally, there are some 16,700 children aged 0 to 16 who live in State-run institutions, such as baby homes, residential care centres and boarding schools.[11] They include three special schools for the blind and eight special schools for the deaf, located throughout the country.

54. The 2008 census indicated a literacy rate of 99.99 per cent for the total population aged over 10 years, with no variation between rural and urban areas, and between women

[10] See UNICEF, "Situation analysis of children and women in the Democratic People's Republic of Korea – 2017", p. 62.

[11] See Ministry of Education and National Commission for UNESCO, "National plan of action on Education for All", p. 7.

and men.[12] In that regard, the Korean Federation for the Protection of the Disabled acknowledged that in practice the literacy rate is probably lower, owing to the fact that many children with disabilities do not attend school. According to a socioeconomic, demographic and health survey carried out in 2014, while school attendance between 5 and 14 years of age appeared to be almost universal, it dropped to 62 per cent between the ages of 15 and 19, and to 16 per cent between the ages of 20 and 24, with stark discrepancies between men and women in both rural and urban areas. With completion of compulsory education at 17 years of age, only a small proportion of children, primarily urban males, were found to be pursuing higher levels of education.[13]

1. Access to primary and secondary education

55. In 2012, a decree was promulgated on the enforcement of universal 12-year compulsory education, extending the time frame for free and compulsory education from 11 to 12 years, which became effective on 1 April 2014. The new system consists of one year of preschool education, five years of primary school and six years of secondary school.[14] According to the Education Commission, all children aged between 5 and 17 follow the 12-year education system, including children with disabilities. Children with physical disabilities and those with "mild" intellectual disabilities are reportedly included in regular or boarding schools, while blind and deaf students are taught separately in special schools. In relation to teacher training, the Special Rapporteur was informed that deaf persons were trained to become teachers in schools for the deaf, which she considers to be a good practice.

56. The Education Commission informed the Special Rapporteur that it did not possess data on the number of children with disabilities who were enrolled in mainstream schools and that those children did not benefit from any kind of reasonable accommodation, curricular adaptation or other measures to support their inclusion. Moreover, children with disabilities faced multiple barriers to accessing education on an equal basis with others, owing to the lack of accessible infrastructure, support and specialized teachers. The Special Rapporteur expresses serious concern that children with disabilities do not attend mainstream schools and when they do, they do not receive quality education. She also received information that the parents of children with intellectual disabilities did not send them to school, not only because of the lack of quality services and of any kind of support, but also because of stigma and poor expectations in the education system of the potential of the children.

57. Similarly, the Special Rapporteur was informed that many parents of deaf and blind children preferred to keep them at home, rather than sending them to distant boarding schools, where they returned home only twice a year, for two months in the winter and one month in the summer. It is also of concern that the curriculum taught in the special schools for the deaf and the blind differs from the curriculum in regular schools, with more emphasis on vocational training. For instance, during her visit to the Pongchon School for the Blind, she was informed that in addition to Braille, orientation and other general education subjects, students learned primarily vocational skills, such as massage therapy, music and arts, agriculture, or handicrafts, which prevented them from entering tertiary education.

58. The Special Rapporteur was also told that only a small proportion of children with other types of impairments, such as those with intellectual disabilities, autistic children, children with cerebral palsy and Down's syndrome, receive education at the Korean Rehabilitation Centre for Children with Disabilities in Pyongyang. This pilot rehabilitation centre is hosted in a regular nursery and provides specialized therapies for up to 25 children

[12] Central Bureau of Statistics (CBS), DPRK 2008 Population Census – National Report, 2009, pp. 109–110.

[13] Central Bureau of Statistics and UNFPA, *Socio-economic, demographic and health survey 2014*, (2015), pp. 37–38.

[14] Democratic People's Republic of Korea - Education for all 2015 national review (2014), pp. 13 and 19.

with disabilities between the ages of 3 and 9. Individual learning plans, including curricular adaptations, accommodation and specialized support, are currently not available at the facility, although they are essential for securing access to quality education on an equal basis with others. The majority of children with disabilities, including those with multiple, intellectual or developmental disabilities, fall outside the school system altogether.

59. The Special Rapporteur urges the Education Commission to take measures for the progressive implementation of an inclusive quality education system and to provide learners with disabilities with the support needed to access education on an equal basis with others. Such measures should entail adjusting the physical environment to make all national kindergartens, schools, colleges and universities accessible, adapting educational materials and learning methodologies, training teachers and giving learners with disabilities the necessary support and reasonable accommodation, including sign language interpretation, audio and Braille materials and personal assistance. She also recommends converting the 11 existing special education schools in resource centres for children with disabilities, and making further efforts to ensure that all children with disabilities, including those who need a high level of support, can access quality education on an equal basis with others.

2. Access to vocational training and higher education

60. The Special Rapporteur was informed that after completing secondary school, persons with disabilities have the opportunity to further their education through specialized vocational training in light industries such as factory or forestry schools, or pursue their education by going to college, including through distance learning. Those who successfully graduate from college can take an examination to be admitted to university. However, she received information that in practice persons with disabilities are rarely given the opportunity to take the entrance examination.

61. It is of concern that very few persons with disabilities (primarily learners with minor physical disabilities) reach tertiary education and if they do, it is without the benefit of the support and accommodation they require. In that context, deaf and blind persons, women with disabilities and persons with intellectual, psychosocial or multiple disabilities have almost no chance of being admitted to university. Further efforts are needed to amplify the career options for the diversity of persons with disabilities, which currently appear to be limited to traditional career paths for persons with disabilities (arts, embroidery, massage therapy etc.), and to increase access to university for all persons with disabilities.

F. Social protection

62. In the Democratic People's Republic of Korea, the State is the sole provider of all living conditions for its citizens, including those with disabilities. Its social protection framework includes, inter alia, free universal health care, 240 days of maternity leave on full pay and the provision of basic food, clothing and housing. According to the law on the protection of persons with disabilities, such persons can benefit from subsidies, pensions and specialized services, including workshops, and scholarships to study.

63. According to the combined second to fourth report of the State party to the Committee on the Elimination of Discrimination against Women, in 2008 the State adopted a social security law (amended in 2012), which sets out the principles according to which social security is provided to people who are unable to work due to old age, sickness or disability. It also sets out the procedure for applying for social security, the disbursement of allowances, the establishment of social security institutions and the obligations of the institutions and enterprises concerned. However, the Special Rapporteur was unable to access this legislation and did not receive adequate information regarding the system. The same applies to the law on the protection of the elderly, mentioned in the same report, according to which older persons receive pensions and subsidies from the State.

64. According to the information available, household doctors make a disability assessment at the local level and the information is then shared at the county, district and provincial levels up to the central level, where information is recorded in a centralized disability management information system. It appears that the registration process entails a

procedure for determining disability founded only on a medical assessment, which should be revised in line with the Convention on the Rights of Persons with Disabilities.

65. Regrettably, the Special Rapporteur was not able to obtain sufficient information regarding the disability certification process, which, she was told, is provided by the Ministry of Labour.

66. The Special Rapporteur noted that the law on the protection of persons with disabilities provides preferential treatment to "honoured ex-soldiers with disabilities and people with disabilities who have performed meritorious services for socialist construction" (art. 7). She was informed that such persons with disabilities benefit from better housing and job opportunities, and have access to health-care facilities that are exclusively for them. Similar provisions are found in the Socialist Constitution, the public health law, the social security law, the law on the protection of the elderly and other legislation. Such provisions and benefits should be extended to all persons with disabilities, not only to a small privileged group.

67. The Special Rapporteur has identified a need to expand the effective coverage of benefits and services to all persons with disabilities, including little persons and those with intellectual, developmental, psychosocial, multiple and severe disabilities, so as to ensure their enjoyment on an equal basis with others and to mainstream disability in all other social protection programmes.

68. Regarding her visit to the Pyongyang primary boarding school, while the Special Rapporteur acknowledges the attention paid to the situation of orphans with and without disabilities, she highlights the need to transition from residential care institutions to family and community-based forms of childcare, such as foster care, adoptive families and other family-like settings, in accordance with articles 20 and 23 of the Convention on the Rights of the Child and article 7 of the Convention on the Rights of Persons with Disabilities.

G. Health

69. The amended public health law of 2012 governs the health policy of the country, which is based on a system of free universal health care. According to official data, in 2014 the country had 1,829 hospitals, including central, provincial, general and specialized hospitals, 55 preventive stations, 6,263 polyclinics and clinics and 682 sanatoriums for preventive and curative care. Everyone receives preventive and curative services provided by some 45,000 household doctors, where one doctor is responsible for about 130 households (see CEDAW/C/PRK/2-4, paras. 150–151). However, despite the high degree of medical coverage, the Minister of Public Health has acknowledged the existence of general shortages in quality medical equipment and medicines, including essential medicines and basic laboratory tests. In that regard, the Special Rapporteur was astonished to learn from several interlocutors that in some hospitals doctors perform surgery, including amputations, without anaesthesia, owing to the lack of sedatives available. Other major shortcomings of the public health system include old infrastructure, a lack of heating, irregular electricity, an unsanitary and irregular water supply and a limited operational budget.

70. During her stay, the Special Rapporteur visited the Okryu children's hospital and two rehabilitation centres in Pyongyang — the Munsu functional rehabilitation centre and the Korean rehabilitation centre for children with disabilities — all of which were well equipped. She was informed that there are no similar facilities and services for persons with disabilities elsewhere in the country. For instance, the Okryu hospital has surgical and neurological departments equipped to handle cases of children with spina bifida, autism and cerebral palsy, which are unavailable outside Pyongyang. Officials explained that these three facilities are model hospitals and centres that the Government intends to replicate across the country and that a new functional rehabilitation centre for persons with disabilities will be built in 2018 in Pyongyang, which will also serve as a training centre for community-based rehabilitation workers from all provinces. The Special Rapporteur encourages the Government to progressively implement disability-specific services in the community in all parts of the country, to ensure the inclusion and autonomy of persons with

disabilities, and does not recommend the creation of new separate facilities for persons with disabilities.

71. The Special Rapporteur was shown the telemedicine network that connects the Okryu children's hospital with 11 provincial paediatric hospitals through optic fibre, connects the latter with some 200 paediatric departments in municipal and county hospitals, and is used to train doctors and other health workers and discuss cases. If fully implemented, it has the potential to reduce inequalities in access to health care between the capital and rural areas.

72. With regard to women with disabilities, the Special Rapporteur was informed that they have access to sexual and reproductive health services and can take decisions concerning family planning. However, the concept of informed consent in general does not appear to be known or sought from persons with disabilities. She received worrisome reports of forced abortion and forced sterilization of women with disabilities and that infanticide is sometimes practiced after the birth of a child with disabilities, but is not in a position to confirm or deny those allegations.

73. The Special Rapporteur notes that the law on the protection of persons with disabilities places an emphasis on the prevention of the occurrence and aggravation of disability (art. 4). While acknowledging the importance of public health campaigns, including on the prevention of diseases or conditions that could lead to impairment, she notes that this issue should fall under the responsibility of the Ministry of Public Health as it addresses the general population. As the Convention on the Rights of Persons with Disabilities does not include disability prevention (apart from the prevention of further disabilities in article 25 (b)), she recommends removing article 4 from the law on the protection of persons with disabilities and inserting it into the public health law.

74. The Special Rapporteur was alarmed to learn from the Ministry of Public Health that all little persons are registered and receive special attention, including trials and research to identify treatments to increase their height. She recommends that these practices be halted and that little persons fall under the overall responsibility of the Korean Federation for the Protection of the Disabled, as is the case for other persons with disabilities.

H. Legal capacity

75. Persons with disabilities can be deprived of their right to legal capacity. It is assumed that some people with disabilities have no legal capacity to take decisions on their own and should be placed under the responsibility of a guardian. Article 50 of the amended law on the protection of persons with disabilities provides for the appointment of such a guardian. The Special Rapporteur was informed that this provision must be read in conjunction with articles 40 and 41 of the family law and article 49 of the civil procedure law, which regulate the appointment of a guardian for those who cannot exercise their legal capacity due to disability.

76. The Special Rapporteur stressed that any provision establishing guardianship systems for persons with disabilities and restricting their legal capacity based on the presumption or existence of a disability are contrary to article 12 of the Convention on the Rights of Persons with Disabilities. She strongly urged the Government to amend such provisions and guarantee that all persons with disabilities retain their legal capacity and are offered support to make their own decisions.

I. Other human rights issues

77. While the rights of persons with psychosocial disabilities is a priority issue for her mandate, the Special Rapporteur regrets that, despite repeated requests, she was unable to visit a psychiatric hospital or to meet any persons with psychosocial disabilities. She profoundly regrets that she was unable to make an assessment of their situation in the country.

78. The Special Rapporteur could not obtain any information regarding the deprivation of liberty of persons with disabilities in the country. Similarly, she did not receive information on access to justice, apart from information about an accommodation procedure contained in the law on criminal procedures and the law on civil procedures on the provision of sign language interpretation. She was informed of one case of a deaf person accused of a crime who was assisted by a sign language interpreter during the trial.

79. In the area of work, out of some 1,200 workshops or light factories for persons with disabilities that were built in the 1950s, the majority are reportedly no longer operational, owing to lack of equipment and the raw materials to produce goods. The Special Rapporteur was informed that when someone acquires a disability, they can opt to work in these factories, where they benefit from reduced working hours and higher salaries. Moreover, the State reportedly provides one month's leave in rehabilitation facilities and six months to war veterans. She was also told that according to the regulations on job placement, institutions and enterprises are obliged to employ former soldiers with disabilities, blind and deaf persons, and other persons with disabilities above degree two, and that they cannot be dismissed because of their disability, unless in unavoidable circumstances. She recommends that there is a transition from separate workshops for persons with disabilities to inclusive workplaces. In that regard, the creation in 2014 of nine self-help groups of persons with and without disabilities working together on income-generating activities, employing some 120 persons with disabilities in total, including women, is a good pilot practice.

IV. The role of the United Nations country team and international cooperation actors

80. In 2016, the Government and the United Nations country team[15] jointly formulated and agreed upon a strategic framework for cooperation that sets out the agreed priorities for United Nations country-level engagement for the period 2017–2021. In the strategic framework food and nutrition security, social development services, resilience and sustainability, and data and development management were identified as the main strategic priorities that the United Nations would seek to address in support of government programmes. The Government and the United Nations also committed to applying a human rights-based approach, gender equality, the Sustainable Development Goals and other principles throughout all programmes.[16]

81. Given the country's protracted humanitarian situation, the humanitarian country team prepares an annual appeal for donors, which includes persons with disabilities among its most vulnerable beneficiaries. However, since 2012 donor funding has declined radically, not only because of the international sanctions and political considerations, but also owing to other factors, such as disruption to fund transfers, lengthy procurement processes and the slow delivery of equipment and supplies.[17]

82. In that context, international cooperation actors should support the effective implementation of the Convention on the Rights of Persons with Disabilities in the country, including through the allocation of adequate financial and human resources to inclusive programmes and to disability-specific projects. The Special Rapporteur also acknowledges the country's openness for exchange and interaction with other countries to learn from their practices in the area of disability, which she considers an opportunity for further engagement.

[15] There are six resident United Nations agencies in the country, the Food and Agriculture Organization of the United Nations, the United Nations Development Programme, UNFPA, UNICEF, the World Food Programme and the World Health Organization, and eight non-resident agencies.

[16] See "Strategic framework for cooperation between the United Nations and the Democratic People's Republic of Korea, 2017-2021", pp. 11–14.

[17] Humanitarian country team and partners, "DPR Korea needs and priorities 2017", p. 15.

83. The Special Rapporteur notes the references to international human rights norms and standards, a human rights-based approach and to persons with disabilities in the strategic framework and the annual "Needs and priorities" document for 2017. Furthermore, she welcomes the increasing efforts for and attentiveness to the rights of persons with disabilities of some United Nations agencies and international cooperation organizations. However, in her unofficial meetings she noted some discrepancies in the level of awareness of disability issues across international cooperation actors.

84. The Special Rapporteur strongly encourages the United Nations country team, the humanitarian country team, the diplomatic community and international cooperation actors to mainstream disability in all their strategies, assessments and programmes, to make all their projects inclusive of persons with disabilities, and to recruit persons with disabilities onto their staff. Moreover, she urges the country team to support the implementation of the Sustainable Development Goals in the Democratic People's Republic of Korea and to include the rights of persons with disabilities in a cross-cutting manner, to truly ensure that no one is left behind.

V. Conclusions and recommendations

A. Conclusions

85. **The Special Rapporteur reiterates her appreciation to the Government of the Democratic People's Republic of Korea for accepting her request to visit the country and by doing so to enable her to learn about the efforts made to advance the situation of persons with disabilities and to identify opportunities for improvement. That invitation and the recent ratification of the Convention on the Rights of Persons with Disabilities constitute encouraging positive indications for the advancement of the rights of persons with disabilities in the country.**

86. **The Special Rapporteur also notes several shortcomings, which prevent persons with disabilities from gaining access to education and services on an equal basis with others and from exercising their legal capacity, and which pose barriers to accessibility. She encourages the Democratic People's Republic of Korea to strengthen its legal and policy frameworks on the rights of persons with disabilities and to move towards the comprehensive implementation, enforcement and monitoring of the Convention. She stresses the need for further efforts to promote the independence and autonomy of persons with disabilities, guarantee their equal recognition as persons before the law and their access to education and work to ensure their social and economic inclusion, and to transition from segregated to inclusive communities.**

87. **The 2030 Development Agenda constitutes a great opportunity to promote disability-inclusive development. The cost of excluding persons with disabilities from the main economy and society is always high, not only for them and their families, but also for the economy of the country. To achieve the commitment of "leaving no one behind" in implementing the Sustainable Development Goals, the Democratic People's Republic of Korea needs to foster the inclusion of persons with disabilities in society and ensure their participation in all national strategies, policies and programmes.**[18]

88. **This is also an opportunity for the Office of the United Nations High Commissioner for Human Rights, United Nations human rights mechanisms, the broader United Nations system and the international community to continue the dialogue in this and other human rights-related areas. Despite some of the challenges encountered during this first visit to the country, many lessons can be drawn for future engagement by other human rights experts. In that regard, country visits by other special procedures mandate holders would be greatly beneficial.**

[18] The report of the Special Rapporteur on disability-inclusive policies (A/71/314) contains useful guidance in this regard.

89. **The Special Rapporteur hopes that her visit and report will have a positive impact on the lives of persons with disabilities and that they will assist the Government in advancing the disability rights agenda. She looks forward to a continued dialogue and collaboration with the State and other actors on the implementation of her recommendations.**

B. Recommendations

Legal, institutional and policy frameworks

90. **The Special Rapporteur recommends that the Government of the Democratic People's Republic of Korea:**

(a) **Ratify the Optional Protocol to the Convention on the Rights of Persons with Disabilities and other international human rights instruments to which the State is not yet a party;**

(b) **Submit the overdue fourth State party reports to the Committee on Economic, Social and Cultural Rights and to the Human Rights Committee as soon as possible and include information regarding persons with disabilities;**

(c) **Consider extending a standing invitation to all special procedures mandate holders to visit the country;**

(d) **Conduct a comprehensive legislative review of the national legal framework with a view to amending or repealing provisions that are contrary to the Convention on the Rights of Persons with Disabilities, including those contained in the Socialist Constitution, the law on the protection of persons with disabilities, the law on the protection and promotion of women's rights, the law on the protection and promotion of children's rights, the family law, the public health law, the law on criminal procedures and the law on civil procedures;**

(e) **Promptly finalize and submit for approval the strategic national action plan for the protection of persons with disabilities, with dedicated budgetary resources, and ensure the participation of persons with disabilities, including children and youth, in its implementation and evaluation;**

(f) **Ensure that all public policies are inclusive of persons with disabilities, and that adequate resources are allocated for their effective implementation at provincial, district and county levels;**

(g) **Continue strengthening the capacities of the Korean Federation for the Protection of the Disabled to coordinate disability issues within the State apparatus and monitor the implementation of the Convention, and accelerate the recruitment of the disability focal points to be located in line ministries with the necessary terms of reference, training and responsibilities to perform their tasks effectively;**

(h) **Designate or set up an independent monitoring mechanism compliant with the Paris Principles to monitor the implementation of the Convention in accordance with article 33 (2).**

Data collection

91. **The Special Rapporteur recommends that the Government of the Democratic People's Republic of Korea:**

(a) **Strengthen the institutional data collection and analysis capacity of the Central Bureau of Statistics and the Korean Federation for the Protection of the Disabled and ensure the collection of data on poverty and on the situation of persons with disabilities, disaggregated, at a minimum, by sex, age and geographic region;**

(b) **Apply the methodology developed by the Washington Group on Disability Statistics in all demographic and other surveys and train enumerators accordingly.**

Stigma and discrimination

92. **The Special Rapporteur recommends that the Government of the Democratic People's Republic of Korea:**

(a) **Develop and carry out awareness-raising programmes to dispel attitudinal barriers and stigma related to persons with disabilities;**

(b) **Sensitize the media to promote a positive image of the diversity of persons with disabilities and the correct use of terminology when referring to persons with and without disabilities;**

(c) **Raise awareness of intellectual and other disabilities that go undetected, such as cerebral palsy, autism, Down's syndrome and spina bifida, including in rural and remote areas of the country, and improve access to services for all persons with disabilities everywhere;**

(d) **Recognize little persons as persons with disabilities protected under the responsibility of the Korean Federation for the Protection of the Disabled.**

Accessibility

93. **The Special Rapporteur recommends that the Government of the Democratic People's Republic of Korea:**

(a) **Apply international standards for universal design and accessibility regulations issued by the Ministry of State Construction Control to the construction and maintenance of all public and private infrastructure, and adopt a time-bound plan to make all existing public services, infrastructure and transport accessible;**

(b) **Adopt regulations to guarantee the provision of information in accessible formats, including information and communications technology.**

Participation

94. **The Special Rapporteur recommends that the Government of the Democratic People's Republic of Korea:**

(a) **Promote and support the establishment of associations representing all persons with disabilities, including little persons and those with physical, intellectual, developmental, psychosocial and multiple impairments;**

(b) **Ensure the participation of the diversity of persons with disabilities, including women and girls, in the development and implementation of laws and policies that directly or indirectly concern them through the organization of country-wide accessible consultations;**

(c) **Increase the representation of persons with disabilities in public functions, including in the Supreme People's Assembly.**

Education

95. **The Special Rapporteur recommends that the Government of the Democratic People's Republic of Korea:**

(a) **Take measures for the implementation of an inclusive quality education system across the country through adjustments to the physical environment, adaptation of educational materials and learning methodologies, teacher training, and the provision of support and accommodation for all students with disabilities;**

(b) **Convert the existing 11 special education schools in resource centres to support the inclusion of all children with disabilities in regular schools;**

(c) **Ensure that all children with disabilities, including those with severe and intellectual disabilities, can access education on an equal basis with others;**

(d) **Expand career options for all persons with disabilities and ensure their access to tertiary education on an equal basis with others.**

Social protection

96. **The Special Rapporteur recommends that the Government of the Democratic People's Republic of Korea:**

(a) **Extend the effective coverage of social protection benefits and services to all persons with disabilities, including little persons and those with intellectual, developmental, psychosocial, multiple and severe impairments;**

(b) **Transition from residential care institutions to family and community-based forms of childcare;**

(c) **Review the disability determination process to incorporate a human rights-based approach.**

Health

97. **The Special Rapporteur recommends that the Government of the Democratic People's Republic of Korea:**

(a) **Provide inclusive disability services in the community at the provincial, district and county levels, and refrain from building separate facilities for persons with disabilities;**

(b) **Provide medical care for persons with disabilities as close as possible to their homes, including access to reproductive health services, and promote their inclusion, autonomy and independence.**

Legal capacity

98. **The Special Rapporteur recommends that the Government of the Democratic People's Republic of Korea:**

(a) **Guarantee the exercise of legal capacity to all persons with disabilities, revoke legislative provisions establishing a guardianship system and other forms of substituted decision-making, and transition to a supported decision-making approach.**

Other issues

99. **The Special Rapporteur recommends that the Government of the Democratic People's Republic of Korea:**

(a) **Make all justice proceedings and courts accessible to the diversity of persons with disabilities, including through the provision of legal aid and information in accessible formats, and adopt protocols for procedural and age-appropriate accommodations;**

(b) **Transition from separate workshops for persons with disabilities to inclusive workplaces;**

(c) **Provide United Nations agencies and other international cooperation actors with unhindered access to vulnerable populations, including persons with disabilities, in all counties and provinces.**

International cooperation

100. **The Special Rapporteur recommends that the United Nations country team, donors and international cooperation actors:**

(a) **Invest resources to support inclusive international cooperation projects and facilitate the provision of disability-specific expertise, capacity-building and know-how to strengthen national capacities;**

(b) **Mainstream disability rights in all strategies, assessments and projects, and recruit persons with disabilities onto their staff;**

(c) **Support State efforts to achieve compliance with the Convention and implement the Sustainable Development Goals in an inclusive manner.**

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Report of the Independent Expert on the enjoyment of human rights by persons with albinism

Note by the Secretariat

The Secretariat has the honour to transmit to the Human Rights Council the report of the Independent Expert on the enjoyment of human rights by persons with albinism pursuant to Council resolution 28/6. In her report, the Independent Expert explores matters concerning the enjoyment of the right to the highest attainable standard of health by persons with albinism. On the basis of information gathered from surveys, reports and country visits, she conceptualizes the multifaceted challenges in the field of health, including disabilities arising from visual impairment and the high number of fatalities caused by skin cancer in certain regions, the applicable norms and standards in international human rights law, the continuing challenges and best practices. In so doing, she discusses contextual factors, as well as exogenous elements, including health determinants. She highlights the important work being carried out by civil society and makes several recommendations centred on the call for more government ownership and initiative in this area.

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Report of the Independent Expert on the enjoyment of human rights by persons with albinism

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I. Introduction

1. The present report is submitted pursuant to resolution 28/6 of the Human Rights Council, in which the Council established the mandate of the Independent Expert on the enjoyment of human rights by persons with albinism.

2. In section II of the report, the Independent Expert provides an overview of the activities undertaken since March 2017, in particular regarding attacks, related human rights violations and discrimination against persons with albinism. In section III, she focuses on the right of persons with albinism to the highest attainable standard of health, particularly with regard to visual impairment and their high susceptibility to skin cancer and related ailments.

II. Activities of the Independent Expert

3. In 2017, the Independent Expert conducted country visits to the United Republic of Tanzania (A/HRC/37/57/Add.1) from 18 to 28 July 2017 and to Fiji from 27 November to 7 December 2017. The report of the mission to Fiji will be presented to the Human Rights Council in March 2019.

4. The report on the Independent Expert's visit to the United Republic of Tanzania contains details of the measures taken by both the Government and civil society to significantly decrease the number of reported attacks against persons with albinism. However, the Independent Expert stresses that progress remains extremely fragile, as the root causes of the attacks are still widespread in the country. During her visit to Fiji, the Independent Expert focused on the measures taken to address and mainstream the right of persons with albinism to the highest standards of health, to combat discrimination and to ensure their full access to education.

A. Regional Action Plan on Albinism in Africa (2017–2021)

5. The Regional Action Plan on Albinism in Africa (2017–2021) to address attacks and related human rights violations against persons with albinism has now been finalized (see A/HRC/37/57/Add.3). The Plan was developed by the Independent Expert through consultations with representatives from the United Nations, the African Union, Governments, organizations of persons with albinism and other civil society organizations. It is based on various recommendations by international bodies and mechanisms, and sets out 15 specific, concrete and time-bound measures in key areas, such as public education and awareness-raising, systematic data collection, research on the root causes of violence, the use of legal and policy frameworks to deter harmful practices related to witchcraft and trafficking in body parts, and measures to fight impunity and to ensure support for victims.

6. The Regional Action Plan was endorsed by the African Commission on Human and Peoples' Rights during its 60th ordinary session in May 2017.[1] In addition to endorsing the Plan, the Commission urged all States parties to the African Charter on Human and Peoples' Rights to take all the measures necessary for its adoption and implementation and invited the relevant organs and bodies of the African Union to give due regard to adapting and implementing the Plan.

7. In that context, the Independent Expert convened[2] a regional meeting in Pretoria in November 2017 with representatives from international organizations and civil society, including organizations of persons with albinism, to design an implementation strategy for the Plan. That strategy is currently being finalized and will be launched in 2018.

[1] Resolution 373 (LX) 2017.

[2] With the University of Pretoria and the Open Society Foundations.

B. Witchcraft-related harmful practices

8. In previous reports (A/HRC/34/59 and A/71/255), the Independent Expert showed how interrelated factors, including witchcraft-related harmful practices, contributed to ongoing outbreaks of attacks and discrimination against persons with albinism.

9. To further the debate, the Independent Expert organized, in Geneva in September 2017, the first-ever systematic and in-depth workshop[3] on witchcraft and human rights. The two-day workshop brought together United Nations experts, academics and members of civil society to discuss the violence associated with such beliefs and practices and their impact, particularly on groups in vulnerable situations, including persons with albinism.

10. Workshop participants addressed the various manifestations of witchcraft, its scope, the difficulties associated with its definition and its links to harmful practices, as well as ritual attacks and killings. In addition, victims of witchcraft-related harmful practices shared their experiences. The workshop was concluded with an identification of best practices, recommendations and suggestions for the way forward (A/HRC/37/57/Add.2).

C. Other activities

11. In addition, the Independent Expert participated in numerous public engagements, including interventions in a multiplicity of local and international media events, conferences, campaigns, consultations and expert meetings, which allowed her to increase awareness among a diverse and extensive audience, provide input, share information and promote good practices with regard to the enjoyment of human rights by persons with albinism.

III. The right to health of persons with albinism

A. Introduction

12. Persons with albinism are entitled to the highest attainable standard of health without discrimination of any kind. Under international human rights law, the content and scope of the right to health are defined by international standards and jurisprudence. Considering the evolutionary nature of those standards, the right to health of persons with albinism requires contextualization and the factoring-in of exogenous issues. That is particularly important because persons with albinism are victims of multiple and intersecting discrimination, which hinders the enjoyment of their right to the highest attainable standard of health.

13. The present report is based on research conducted and information collected by the Independent Expert through country visits, academic research, questionnaires sent to member States, organizations serving persons with albinism and other non-governmental organizations.[4]

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[3] With the University of Lancaster, the Witchcraft and Human Rights Information Network, the Special Representative of the Secretary-General on Violence against Children, the Special Rapporteur on violence against women, its causes and consequences, and the Special Rapporteur on extrajudicial, summary or arbitrary executions.

[4] Member States include Cuba, Honduras, Kuwait and Slovenia. Contributions were submitted by the following organizations of persons with albinism: the Albino Network Association of Nigeria; Association Ivoirienne pour la Promotion des Femmes Albinos; Association pour la Promotion des Albinos au Cameroun; Connexion Worldwide, Benin; Mwanza Albino Society, United Republic of Tanzania; Organization of Persons with Albinism in Rwanda; Portail des Droits des Personnes Handicapées en Afrique de l'Ouest, Mali; Rwanda Albinism Society; the Source of the Nile Union of Persons with Albinism, Uganda; and Stukie Motsa Foundation, Swaziland. Information was received from the non-governmental organization Kilimanjaro Sunscreen (KiliSun) and the Kilimanjaro Sunscreen Production Unit, United Republic of Tanzania.

B. Condition of albinism

14. Throughout the world, people are born with albinism, which is a relatively rare, non-contagious, genetically inherited condition that affects people regardless of ethnicity or gender. In order for a person to be affected by albinism, both parents must carry the gene. In such cases, there is a 25 per cent chance at each pregnancy that a child will be born with albinism. The condition is characterized by a significant deficit in the production of melanin, which results in the partial or complete absence of pigment in any part or all of the skin, hair and eyes.

15. There are different types of albinism. The most common and visible type is oculocutaneous albinism, which affects all of the skin, hair and eyes. Within this type, there are various subtypes, which may reflect varying degrees of melanin pigment deficiency.[4] The main subtypes of oculocutaneous albinism are tyrosinase negative albinism and tyrosinase positive albinism. In tyrosinase negative albinism, there is little or no production of melanin; it is often characterized by white hair and opaque or transparent irises. In tyrosinase positive albinism, which is the more prevalent subtype, particularly in African countries, some melanin is produced; it is characterized by yellow-blonde or sandy-coloured hair and grey to light brown irises. Less common forms of albinism include ocular albinism, which affects the eyes alone, and Hermansky-Pudlak syndrome, which is albinism with bleeding and bowel (colitis) disorders, and lung diseases.

16. In addition to significantly affecting appearance, albinism often results in two congenital permanent health conditions: visual impairments to varying degrees and high susceptibility to ultraviolet-induced skin damage, in particular skin cancer.

C. Exogenous health determinants

17. The enjoyment of the right to health by persons with albinism, in particular regarding visual impairment and the susceptibility of the skin to solar damage and cancer, requires consideration of exogenous determinants of health. Visual impairment relates to a condition of the body and leads to disability insofar as the manner in which "environment and society respond to that impairment".[5] As recognized in preamble to the Convention on the Rights of Persons with Disabilities, disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinder their full and effective participation in society on an equal basis with others. Similarly, the Committee on Economic, Social and Cultural Rights specifies that the right to health embraces a wide range of socioeconomic factors that promote conditions under which people can lead a healthy life. Those extend to the underlying determinants of health, such as food and nutrition, housing, access to safe and potable water and adequate sanitation, safe and healthy working conditions, and a healthy environment.[6] For instance, in the Bhatti Tribe of Pakistan, in which about 5 per cent of its members are persons with albinism, a study found that "most of them are economically poor and cannot afford to buy sun protection medicines and clothing required for this condition".[8] Likewise, in Nigeria, the barriers to eye care faced by persons with albinism include poor awareness, non-availability

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[4] See, for example, Octaldine R. McBride, "Oculocutaneous albinism: an African perspective", *British and Irish Orthoptic Journal*, vol. 11 (2014), pp. 3–8, at p. 3: "Melanin is a photo-protective protein whose role in the skin is to absorb ultraviolet (UV) light and prevent damage; without melanin the skin is more prone to sunburn and skin cancer. Lack of melanin results in a triad of signs — pale skin, light hair and pale iris colour — but the consequence of [oculocutaneous albinism] is impaired visual acuity (VA)."

[5] Theresia Degener, "Disability in a human rights context", *Laws*, vol. 5, No. 3 (2016).

[6] See general comment No. 14 (2000) on the right to the highest attainable standard of health, para. 4.

[8] Azam Jah Samdani and Bahram Khan Khoso, "A unique albino village of Bhatti tribe in rural Sindh, Pakistan, with oculocutaneous albinism manifestations: an epidemiological study", *Iranian Journal of Dermatology* (2009).

of such care, financial constraints and limited accessibility, notably regarding transportation due to the uneven spatial distribution of services.[9]

18. In addition to the socioeconomic and environmental factors, a range of other exogenous determinants greatly, and often negatively, affect the enjoyment of the right to health by persons with albinism. Those factors include myths, discrimination and stigmatization, which are often conveyed and reinforced through popular culture, such as folklore, media and film, and exacerbated by a widespread lack of awareness about albinism, including among health professionals. Any consideration of such exogenous determinants requires "a reorientation in dealing with albinism — away from just medical intervention to treating it as a social construct requiring a holistic approach".[10]

19. In sub-Saharan Africa, it has been widely documented that myths and misbeliefs surrounding persons with albinism have led to witchcraft-related harmful practices, involving the use of their body parts obtained through brutal attacks and mutilations.[11] In that region, the psychological impact of stigmatization and fear of being attacked greatly affect the health of persons with albinism. For instance, in the United Republic of Tanzania, persons with albinism — victims or not — often exhibit a high level of anxiety, including hypervigilance scanning, which is often a response to a ubiquitous fear in all environments.

20. Moreover, it is reported that persons with albinism — particularly when there is a strong visible contrast between their appearance and that of the general population — are rejected, shunned and excluded from their community, owing to the myths surrounding the condition and related stigmatization.

21. Climate is also a significant risk factor. Regions of high sun exposure represent a particular threat to persons with albinism, such as in the Sahel, equatorial countries, the South Pacific and South America.

D. International normative framework

22. Article 12 of the International Covenant on Economic, Social and Cultural Rights provides the most comprehensive normative framework on the right to the highest attainable standard of health. It is buttressed by specific provisions in other international[12] and regional[13] human rights instruments.

The right to health

23. Pursuant to that article, States parties should take all appropriate measures to ensure access for persons with albinism to gender-sensitive health services, including health-related rehabilitation. In particular, States parties shall provide tailored health services for the condition of albinism, and ensure that such health services are made available as close

[9] N.N. Udeh and others, "Oculocutaneous albinism: identifying and overcoming barriers to vision care in a Nigerian population", *Journal of Community Health*, vol. 39, No. 3 (2014), pp. 508–513.

[10] R.J. Gaigher, P.M. Lund and E. Makuya, "A sociological study of children with albinism at a special school in the Limpopo province", *Curationis* (2002).

[11] A/HRC/34/59.

[12] The right to health is also recognized in the following international legal instruments: International Convention on the Elimination of All Forms of Racial Discrimination, art. 5 (e) (iv); Convention on the Elimination of All Forms of Discrimination against Women, arts. 11 (1) (f), 12 and 14 (2) (b); Convention on the Rights of the Child, art. 24; International Convention on the Protection of the Rights of All Migrant Workers and Members of Their Families, arts. 28, 43 (e) and 45 (c); and Convention on the Rights of Persons with Disabilities, art. 25.

[13] The right to health is also recognized in several regional instruments, such as the African Charter on Human and Peoples' Rights, the Additional Protocol to the American Convention on Human Rights in the Area of Economic, Social and Cultural Rights, known as the Protocol of San Salvador (1988) and the European Social Charter (1961, revised in 1996). The American Convention on Human Rights (1969) and the Convention for the Protection of Human Rights and Fundamental Freedoms (1950) contain provisions related to health, such as the right to life, the prohibition on torture and other cruel, inhuman or degrading treatment or punishment, and the right to family and private life.

as possible to local communities where persons with albinism live. Furthermore, States parties shall require health professionals to provide care of the same quality to persons with albinism as is available to others; prohibit discrimination against persons with albinism in the provision of health services; and prevent discriminatory denial of health care or health services on the basis of disability or colour.

24. The right to health also includes four interrelated elements: availability, accessibility, acceptability and quality. In addition, it entails ensuring access to an adequate system of health protection without discrimination, the right to prevention and treatment of illnesses, the right to access essential medicines, the provision of health-related education and information, and the participation of those concerned in health-related decision-making.[14]

The rights of persons with disabilities

25. Persons with albinism are entitled to the same rights and standards enjoyed by persons with disabilities, owing to the lack of sufficient melanin in their eyes and skin, which results in sensitivity to bright light, visual impairment, susceptibility to skin cancer and various associated barriers in society. It is essential to reassert that human rights are inalienable, regardless of health or disability status. In accordance with the Convention on the Rights of Persons with Disabilities, States have a duty to provide reasonable accommodation in order to ensure de facto equality of persons with disabilities.[15] The Convention also recognizes the right to the enjoyment of the highest attainable standard of health, without discrimination on the basis of disability.[16]

Equality and non-discrimination

26. Persons with albinism also face discrimination on the basis of colour, which leads to significant barriers to the enjoyment of the right to health. In that regard, the Committee on the Elimination of Racial Discrimination recognizes that persons with albinism suffer from racial discrimination, as it is discrimination based on colour, one of the prohibited grounds of racial discrimination listed in article 1 of the International Convention on the Elimination of All Forms of Racial Discrimination.[17]

27. Discrimination against persons with albinism on the basis of colour manifests itself in a variety of forms. They include harmful practices,[18] and physical attacks and mutilation motivated by witchcraft-related beliefs and practices, which often lead to death, as reported in 28 countries in sub-Saharan Africa. In that region, pre-existing conditions include a widespread belief in witchcraft and, in particular, ambiguity between the practice of witchdoctors and practice of traditional medicine.[19]

28. In that regard, the International Convention on the Elimination of All Forms of Racial Discrimination lays down the obligations of States parties to prohibit and eliminate racial discrimination in all its forms and to guarantee the right of everyone, without distinction as to race, colour, or national or ethnic origin, to public health, medical care, social security and social services.[20] Therefore, under the Convention, persons affected by racial discrimination, including persons with albinism, are entitled to benefit from special measures by States parties until de facto equality is guaranteed.[21]

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[14] Committee on Economic, Social and Cultural Rights, general comment No. 14.

[15] Arts. 2 and 5.

[16] Art. 25.

[17] See CERD/C/ZAF/CO/4-8, paras. 20–21.

[18] Joint general recommendation No. 31 of the Committee on the Elimination of Discrimination against Women/general comment No. 18 of the Committee on the Rights of the Child (2014) on harmful practices.

[19] See A/HRC/34/59, para. 56.

[20] Art. 5.

[21] General recommendation No. 32 (2009) on the meaning and scope of special measures in the Convention.

Intersecting and multiple discrimination

29. Persons with albinism are discriminated against on the basis of intersecting grounds, largely based on disability and colour. According to reports and direct observation, discrimination based on colour exacerbates the consequences of disability, in particular when there is high degree of contrast between the colouring of persons with albinism and that of the dominant population. According to Patricia Lund, in sub-Saharan Africa for example, "this appearance, so strikingly different from normally pigmented family members and the rest of the black community, results in problems of acceptance and social integration for those affected."[22]

30. In other words, discrimination against persons with albinism should be understood as a specific situation stemming from the intersection of both disability and colour. Also, multiple discrimination affects subgroups and individuals among people with albinism. For instance, persons with albinism who are women and those affected by HIV/AIDS face aggravated discrimination.[23]

31. Therefore, an understanding of the challenges and identification of promising practices to ensure the right of persons with albinism to the highest attainable standard of physical and mental health require a holistic approach. Such an approach should also address the contextual and exogenous determinants that underpin specific situations at the intersection of both disability and colour, which manifest themselves with different degrees of severity according to the specific context.

IV. Issues and challenges

32. The most pressing health issue faced by persons with albinism is skin cancer. That fact has been firmly established on the basis of several studies and consultations with civil society organizations, particularly those working with persons with albinism. In addition to skin cancer, other urgent health issues include visual impairment and mental health.

33. Persons with albinism are also subject to other health problems not linked to the condition of albinism. Those include common conditions and illnesses to which they have become more vulnerable, owing to poverty and pre-existing discrimination and neglect of albinism in the health and social services system, in general. Organizations of persons with albinism reported specific health problems, such as malnutrition and dehydration, tropical diseases, such as malaria and typhoid fever, infectious diseases, HIV/AIDS, cholera and chronic non-communicable diseases.

34. At present, the enjoyment of the right to the highest standard of mental and physical health by persons with albinism is far from a reality. As a consequence, health issues and intersecting discrimination in the context of exogenous factors have an impact on the enjoyment of other human rights, such as the right to life and socioeconomic rights.

A. Impact of health issues on the right to life

35. The most serious health issue affecting the enjoyment of the right to life by persons with albinism is their susceptibility to skin cancer. In addition, the discrimination and stigmatization arising from skin colour leads to immediate life-threatening crimes in contexts in which witchcraft-related misbeliefs and harmful practices are widespread.

High susceptibility to skin cancer

36. It has been indicated in several reports that most persons with albinism in sub-Saharan Africa die from skin cancer between the ages of 30 and 40 years.[24] In the case of

[22] P.M. Lund, "Oculocutaneous albinism in southern Africa: population structure, health and genetic care", *Annals of Human Biology*, vol. 32, No. 2 (2005), pp. 168–173, at pp. 168–169.

[23] Submission of the Association Ivoirienne pour la Promotion des Femmes Albinos.

[24] Submissions of Connexion Worldwide and the Source of the Nile Union of Persons with Albinism.

the United Republic of Tanzania, which has been a prime beneficiary of multiple interventions on the issue, and consequently accounts for a significant amount of data on the matter, it has been reported that half the population of persons with albinism "will develop advanced skin cancer between 20 and 30 years of age, with less than 2 per cent of albino children in Tanzania living to be 40 years of age".[25] It was also indicated in an earlier study that "chronic skin damage was found in all those with albinism by 12 months of age".[26] In those circumstances, the prospects of having limited or no access to preventive measures and treatments for skin cancer would inevitably lead to premature although preventable death — all of this despite the fact that the susceptibility of the skin of a person with albinism to cancer and other solar damage has been known for at least half century.[27] The risk is exacerbated in sunny climates closer to the equator, but it is still a permanent and universal risk for persons with albinism throughout the world. In Cuba, where persons with albinism enjoy free access to the health system, a small number of cases of skin cancer are reported.[28]

37. In poor countries, "sunscreens are prohibitively expensive, leading to a focus on sun avoidance and protection from an early age".[29] At schools in sunny climates, sun exposure may also differ between boys and girls as they tend to have different leisure activities and wear different clothes. The Association Ivoirienne pour la Promotion des Femmes Albinos reports that women may be more vulnerable to sun exposure due to the type of clothes they wear and their daily activities, including childcare. In their study of children with albinism in a specialized school in South Africa, Patricia Lund and Julie Taylor observed that boys play football outdoors, while girls prefer activities in shaded areas. In that regard, data collected by the only cancer institute in the United Republic of Tanzania shows that men and boys are significantly overrepresented at their clinic. Thus, a gender perspective is required in devising responses to the susceptibility of persons with albinism to skin cancer. However, it is essential to remember that sunburn and similar damage could still occur in the shade. That is why adequate protective clothes are key in sun avoidance and protection.

38. Outdoor working conditions aggravate the risks and the prevalence of skin cancer among persons with albinism, particularly in rural areas.[30] Limited employment opportunities and vocational training condemn most to outdoor income-generating activities under extended sun exposure. Furthermore, a lack of health facilities and health programmes, including screening and treatment, directly contribute to the high mortality rate of persons with albinism owing to skin cancer.

39. For those who already have skin cancer, treatment is often not available. In Benin, for instance, Connexion Worldwide reports that they are not aware of any specialized centre for screening and treatment of skin cancer. In Uganda, the Source of the Nile Union of Persons with Albinism reports that the only radiotherapy machine in the country has been broken for a long period. Furthermore, the risk of skin cancer is higher when persons with albinism seek help too late after the appearance of the first symptoms, or fail to follow preventive measures or complete their treatment regimen.[31] Factors accounting for those issues include the lack of priority accorded to prevention measures given the need for immediate survival, self-isolation to avoid further stigmatization, fear of attack, lack of information and lack of financial means to cover the cost of transport to health centres and other costs.

[25] Geraldine R. McBride, "Oculocutaneous albinism: an African perspective", p. 11.

[26] Patricia M. Lund and Julie S. Taylor, "Lack of adequate sun protection for children with oculocutaneous albinism in South Africa", *BMC Public Health*, vol. 8 (2008).

[27] A.N. Okoro, "Albinism in Nigeria: A clinical and social study", *British Journal of Dermatology*, vol. 93, No. 5 (1975), pp. 485–492.

[28] Submission of Cuba.

[29] P.M. Lund, "Oculocutaneous albinism in southern Africa".

[30] Submission of Connexion Worldwide.

[31] Geraldine R. McBride, "Oculocutaneous albinism: an African perspective".

Attacks, rape, mutilation, infanticide and trafficking of body parts

40. Discrimination and stigmatization against persons with albinism, owing to myths and misbeliefs, lead to several human rights violations. Foremost is the violation of the right to life, which often takes the form of attacks, mutilations, trafficking of body parts and infanticide. For instance, in Benin, there are reports that infanticide has been carried out based on the misbelief that children with albinism cause misfortune.[32] Similarly, in Zimbabwe, it is reported that, "traditionally, children with albinism were associated with witchcraft and bad omens and were killed at birth".[33] Instances of infanticide have also been reported in Swaziland.[34] Furthermore, there is also the prevalent "death myth", which holds that persons with albinism do not die but simply disappear.

41. In some regions, it has been reported that persons with albinism are the subject of positive misbeliefs, such as being considered gods or quasi-deities, as in southern Benin[35] or in the Kuna Lands in Panama.[36] In those cases, the misbeliefs do not generate a direct threat. However, their apparently benign origin is not to be automatically looked upon as favourable since they are still misbeliefs, ignorant of the condition of albinism. Such misbeliefs are also dangerous because they associate the value, dignity and, ultimately, the human rights of persons with albinism with a subjective interpretation, which could change over time.

42. The life expectancy of persons with albinism, particularly children and women with albinism, is also put at risk by harmful practices based on misbelief and witchcraft. A number of countries in sub-Saharan Africa continue to be affected by the ritual defilement and rape of girls and women with albinism because of the belief that their body parts have magic or medicinal qualities. This situation has been caused by the myth that having sexual intercourse with a woman with albinism can cure HIV/AIDS. As a result, persons with albinism, in particular women and children, are more susceptible to HIV infections and face further stigmatization and self-isolation. Persons with albinism who are HIV-positive may not seek treatment for fear of being easily identified. All those factors constitute a multifaceted barrier affecting the right to live in dignity and the life expectancy of persons with albinism, in particular, women and children with albinism.

II. Impact of health issues on socioeconomic rights

43. The absence of reasonable accommodation for visual impairment and health care regarding susceptibility to cancer hamper the enjoyment of the right to health, as well as other socioeconomic rights. Access to education and employment by persons with albinism are particularly undermined.

Right to education

44. Visual impairment and the associated lack of reasonable accommodation represent a serious barrier to keeping children with albinism in school. In addition to stigmatization and bullying, visual impairment partly accounts for low school attendance. The high susceptibility of skin to cancer and other conditions also act as barriers in accessing education when reasonable accommodation is not provided. For instance, participants at the first Fiji Albinism Awareness Symposium, held in 2015, observed that vision aids and sunscreen were not generally available for children in village schools.

45. Often, the absence of reasonable accommodation at school is due to the lack of awareness about albinism among communities and teachers. For instance, the belief that

[32] Submission of Connexion Worldwide.

[33] J.S. Taylor and P.M. Lund, "Experiences of a feasibility study of children with albinism in Zimbabwe: a discussion paper", *International Journal of Nursing Studies*, vol. 45, No. 8 (2007), p. 1250.

[34] Submission of Stakie Motsa Foundation, Swaziland.

[35] Submission of Connexion Worldwide.

[36] P. Acambrun, "Oculocutaneous albinism: clinical, historical and anthropological aspects", *Archives de pédiatrie: organe officiel de la Société française de pédiatrie*, vol. 5, No. 8 (August 1998), pp. 906–907.

children with albinism develop blindness is widespread across the medical and educational sectors and is resulting in children being taught Braille when they do not require it. In some countries those with albinism are registered as "legally blind" or "blind", although this does not mean they have no vision."

Right to work

40. The overall health situation of persons with albinism described above, along with discrimination and stigmatization, represent a barrier to favourable conditions of work, in particular regarding safe and healthy working conditions.[74] For instance, in a study on members of the Lunga community with albinism living in a remote area of Zimbabwe, it was highlighted that sensitive skin and photophobia prohibited them from participating in agricultural and fishing activities and that very few other opportunities for work existed.[75]

41. Furthermore, the appearance of skin cancer lesions on persons with albinism, often confused with albinism itself due to the lack of awareness, leads to even more stigmatization and exposes persons with albinism to further discrimination, particularly when seeking employment.[76] In Pakistan, many persons with albinism "attribute their cosmetic disability as one of the reasons for their joblessness".[77] Similarly, in Nigeria "social discrimination, often associated with albinism, constitutes a major obstacle to building of social relationships and finding/maintaining an occupation among persons with albinism".[78] Reported examples of discrimination and stigmatization in India include refusing to provide work placements and having to sign a declaration to release a college from its duty to provide placements to students.[79] Similarly, in Spain, it was reported that persons with albinism had been discriminated against based on their physical appearance, in particular in employment that required direct contact with clients. Potential employers considered that their appearance could have a negative impact on their business.[80]

Women and girls' rights

42. As pointed out above, women and children, in particular girls, suffer multiple discrimination owing to targeted rape by persons with HFS/ASPS. Consequently, survivors of sexual violence can experience increased health complications, such as post-traumatic stress disorder, pregnancy and sexually transmitted infections.[81]

C. Psychosocial impact and mental health

43. Mental health has been identified by persons with albinism as one of their major health issues.[82] The issue is global, as the psychological and mental "stress" of stigmatization is reported worldwide. The need for psychological and rehabilitative support should not be underestimated, not only for those that have survived attacks and mutilations, but also for all persons with albinism who experience fear, bullying, stigmatization, lack of

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[74] P. Lynch, P. Lund and B. Masuku, "Identifying strategies to enhance the educational inclusion of visually impaired children with albinism in Malawi", *International Journal of Educational Development*, vol. 30 (2010), pp. 216–224.

[75] International Covenant on Economic, Social and Cultural Rights, art. 7 (b).

[76] Patricia M. Lund and others, "Underestimated albinism in an isolated Lunga community in Zimbabwe", *Journal of Medical Genetics*, vol. 34, No. 4 (1997), pp. 333–338.

[77] See A/HRC/31/63, para. 39.

[78] Alam Sab Samadani and Bahram Khan Khoso, "A unique albino village of Bhatti tribe in rural Sindh, Pakistan, with oculocutaneous albinism manifestations: an epidemiological study".

[79] S.N. Ukoh and others, "Oculocutaneous albinism: identifying and overcoming barriers to vision care in a Nigerian population", p. 7.2.

[80] Information from persons with albinism.

[81] Asociación de Ayuda a Personas con Albinismo, Spain.

[82] Under the Same Sun, "Survey on albinism and social discrimination", 2017.

[83] Information received from persons with albinism.

social life, rejection by families and isolation, leading to depression and mental illness.[49] In Kuwait, for instance, persons with albinism face psychological and social challenges, although they benefit from health care and are not the subject of superstitious beliefs.[50]

50. In Brazil, a study found that the quality of life of persons with albinism is not only affected by poor vision and skin lesions, but also by social stigmatization. Similarly, in South Africa, research highlights that "it is often the negative response to albinism by others that is more hurtful, especially to children, than having to cope with the condition itself".[51] In Côte d'Ivoire, persons with albinism bear testament to the fact that discrimination and exclusion lead to the loss of self-esteem, isolation, sleep disorders and attempted suicide.[52]

51. In Abuja State in Nigeria, a study found that elderly people with albinism experienced several psychosocial problems, such as harassment, abandonment, neglect, withdrawal, isolation, rejection, divorce, labelling, stigmatization, suspicion, frustration and limited opportunities.[53]

52. The oppressiveness of isolation has been observed in Pakistan, where persons with albinism felt different, abnormal, abandoned and helpless, as they were excluded from health care and services.[54] In Zimbabwe, "The Zimbabwe Albino Society insists ... that many families keep children with albinism hidden at home, not sending them to school because of the associated stigma and bullying from both children and adults. Consequently, self-esteem is extremely low in children with albinism."[55]

53. Another negative impact on mental health is caused by the aggravated discrimination of those subject to the stigmatization triggered by the appearance of skin cancer lesions on persons with albinism, which, in several countries, are mistakenly perceived to be a natural part of albinism.[56] Indeed, the "skin, being the largest organ in the body, carries immense psychological significance".[57] Therefore, "disfiguring skin disorders ... may negatively distort a patient's body image".[58]

54. Furthermore, such stigmatization may have far-reaching psychopathological consequences, such as self-exclusion from services, alienation and social withdrawal, loss of identity, poor self-image, depression and anxiety.[59] With regard to self-exclusion, this has been observed even in institutions of higher education. A study on the beliefs and stereotypes concerning albinism at a South African university found that "students with albinism tend[ed] to exclude themselves from the rest of the student community to avoid discrimination and stereotypes around their condition".[60]

55. Social isolation strategies often have negative psychological consequences, such as depression and anxiety. Such an impact also derives from perceived stigmatization, which "relates to feelings of shame and the oppressive fear of enacted stigma and predicament, the

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[49] Submission of Fórum das Lutas dos Povos Hipoalbinos e Amigos do Albinismo - Forpah Albinismo Worldwide and the Rwanda Albinism Society.

[50] Submission of Kuwait.

[51] P.M. Lund, "Understanding albinism in southern Africa", pp. 175, 177.

[52] Submission of Association Ivoirienne pour la Promotion des Enfants Albinos.

[53] Ayonma Babatunde Adekanye, Omosanya Folorunsho Ogini and Alao Moses Taiwo, "Health and psychosocial complaints of elderly albinos in Ondo State, Nigeria", Indian Journal of Gerontology, vol. 24, No. 1 (2010), pp. 364–381.

[54] Asim Ali Nawabi and Bahram Khan Khattak, "A unique albino village of Bkaito tribe in rural South, Pakistan, with multicentauric albinism manifestations: an epidemiological study".

[55] T.L. Taylor and P.M. Lund, "Experiences of a knowbility study of children with albinism in Zimbabwe: a discussion paper", p. 1270.

[56] See A/HRC/11/4/Add.3, para. 39.

[57] I. Sukwianta M. Iskandar and others, "Quality of life of subjects with leprosy and albinism", International Journal of Psychiatry, Disease Journal, vol. 8, No. 8 (2010), pp. 1–6.

[58] Ibid., abstract.

[59] Kolobelo Dhanti, Nomsimbeko Jula and Eleanor Ross, "Being black in a white skin: beliefs and stereotypes around albinism at a South African university", African Journal of Disability, vol. 1, No. 1 (2012).

[60] Ibid., p. 6.

stigmatized persons to behaviours that avoid exposing their condition to protect themselves from experiencing discrimination".[47]

56. The emergence and manifestation of stigmatization "represent the intersection of psychological processes with the cultural construction of the condition".[48] In the case of persons with albinism, Carolyn Palmer observed that myths, stereotypes and self-perception did have an impact on self-esteem.[49] Regarding the impact of culture, research conducted in Malawi found that children with albinism and their families experienced "a range of cultural and social events that impact strongly and negatively on their mental and social well-being".[50]

57. Similarly, in Zimbabwe, it was reported that "in a society where albinism is [accepted] in myth and superstition, regarded as a curse and contagion, affected families lack a supportive environment and often felt isolated and helpless".[51] Thus, families are also subject to the impact of stigmatization, apart from cases in which parents and family reject children with albinism.

D. Health of displaced persons

58. When displaced, persons with albinism face particular risks, such as a heightened risk of violence, particularly violence related to witchcraft practices, exploitation and abuse, including sexual and gender-based violence, as well as high levels of stigmatization. In addition, persons with albinism, as persons with disabilities, also face numerous barriers in access to humanitarian assistance, education, employment, health care and other services, and are often excluded from decision-making processes and leadership opportunities.

59. In certain countries, persons with albinism have fled and continue to flee their homes in the wake of attacks. In the United Republic of Tanzania, as a temporary protection measure, certain schools and centres have been designated as centres of refuge for persons with albinism.[52] Most of these are government-run and a few others are private. The designated schools were originally designed for a limited number of people with particular disabilities and special needs. However, as an emergency measure in response to attacks, some of them have had to accept an unsustainable number of persons with albinism who are seeking protection. In addition, such shelters can no longer be considered temporary, and have ceased to be considered as exceptional emergency measures. Other less formalized camps of refuge, such as police stations, have been reported in other countries, such as Burundi. However, up-to-date information on those centres is sparse.[53]

60. In an assessment of the situation in the United Republic of Tanzania carried out in 2015 by the African Committee of Experts on the Rights and Welfare of the Child, the Committee noted "the deteriorating health conditions of the children".[54] They further elaborated that children at one of the main centres, Buhangija, were suffering from various forms of health-related challenges. For instance, many could not afford simple remedies,

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[47] Ibid., p. 8.

[48] Ibid., p. 1.

[49] Carolyn Palmer, "Myths, stereotypes and self-perception: the impact of albinism on self-esteem" British Journal of Visual Impairment, vol. 25, No. 1 (2007), pp. 144–154.

[50] P. Lynch, P. Lund and R. Mkandi, "Identifying strategies to enhance the educational inclusion of visually impaired children with albinism in Malawi", p. 6.

[51] J.S. Taylor and P.M. Lund, "Experiences of a household study of children with albinism in Zimbabwe: a discussion paper", p. 1291.

[52] See http://internet.ohchr.org/Countries/ZA/Shared%20Documents/TZA/INT_CRC_NGO_TZA_18032_E.pdf.

[53] International Federation of Red Cross and Red Crescent Societies, "Through albino eyes: the plight of albino people in Africa evokes Red Cross response". Available at http://reliefweb.int/sites/reliefweb.int/files/resources/E49262187152387949C1257673004A2F4-Full_Report.pdf.

[54] [illegible] of children with albinism in temporary holding shelters", (2016), p. 7.

such as sunscreen, that would protect them from the elevated risk of developing skin cancer. A medical screening camp found out that 80 per cent of the children had sunburns and signs of pre-cancer. Most of the children with albinism had visual impairments, fungus, severe wounds on their skin and suffered from complicated health problems accompanied by high fever. It was also indicated that malaria was a major challenge.[57] The dispensary and sickbay on site was found to be too small and ill-equipped to attend to those issues, such that the health of the children was severely endangered.

61. In 2017, the Independent Expert visited some of those centres, including Buhangija, and noted some improvements. However, she also pointed out that more needed to be done, including to ensure implementation of plans to increase living accommodation, the provision of adequate meals and the safe reintegration of residents back into their families and communities.[58]

F. Health and sustainable development

62. Human rights are increasingly recognized as essential to sustainable development and are the main aim of the Sustainable Development Goals.[59] The goals refer to the core content of the right to health, namely ensuring healthy lives and promoting well-being for all at all ages. To that end, specific targets are listed, including those particularly relevant to the situation of persons with albinism. They include universal access to health-care services, access to quality essential health-care services, financial risk protection, and access to affordable essential medicines and vaccines.[60]

63. Furthermore, a key principle of the Sustainable Development Goals is to leave no one behind. This is repeated seven times throughout the 2030 Agenda and applies to sectional goals, including on health. Persons with albinism have historically been left behind in terms of health services. A quintessential example is the absence of sunscreen on the list of essential medicines of many countries that have sunny climates and therefore the lack of access to such products.

64. That lack of access to a fundamental health product for persons with albinism leads to loss of life. Some may view such a loss as a mere drop in the economic bucket, since persons with albinism are a minority quantitatively speaking. Yet, the loss of one life is one too many and such a view would not be in accordance with the unconditional nature of fundamental human rights, particularly the right to life, or the prohibition of discrimination in implementing States' obligations deriving from the right to health. Finally, such a view is at odds with the Sustainable Development Goals, which are aimed at reaching everyone, beginning initially with those furthest behind.

65. The Sustainable Development Goals provide a framework for action and underpin the priority accorded to health initiatives by the Independent Expert, including through the Regional Action Plan on Albinism in Africa (2017–2021), which she developed with multiple stakeholders in sub-Saharan Africa.

F. Health financing

66. Persons with albinism are particularly vulnerable in low-income countries, in which they are often poor and public health services are limited.[61] In such countries, Governments often face many challenges in guaranteeing the progressive realization of the right to health, in accordance with international human rights obligations. At the same time, it is reported that many persons with albinism face the likelihood of early death from skin cancer — a condition that is preventable with basic and affordable interventions. Moreover, the

[57] Ibid., p. 8.
[58] See www.ohchr.org/EN/NewsEvents/Pages/DisplayNews.aspx?NewsID=21915&LangID=E.
[59] See www.ohchr.org/EN/Issues/MDG/Pages/The2030Agenda.aspx.
[60] See targets 3.7 and 3.8 of the Sustainable Development Goals.
[61] See A/72/169, para. 19.

majority of persons with albinism do not have access to, or are unable to afford, the necessary protective devices, whether for skin cancer prevention or to accommodate visual impairment.[72]

67. In this context and in accordance with international human rights law, States have the immediate obligation to ensure, at the very least, minimum essential levels of the right to health for persons with albinism,[73] to take steps towards the realization of that right[74] and to refrain from discrimination against persons with albinism.[75] In that regard, States should prioritize health resources for the most poor and marginalized, even in the face of barriers,[76] and adopt or facilitate low-cost measures that would have an immediate impact on the health of persons with albinism, such as including sunscreen in the list of essential drugs and providing sun protection clothing and devices.

68. States should resort to international cooperation and external funding when resources are scarce. They should support the work of organizations and agencies developing and implementing programmes on the right to health of persons with albinism. In that regard, the Committee on Economic, Social and Cultural Rights recognizes that non-State actors — in addition to States, which are the primary duty-bearers — should also bear responsibility for the right to health. States parties should therefore provide an environment that facilitates the discharge of those responsibilities.[77]

69. Local governments can also play a pivotal role, as reported by the Source of the Nile Union of Persons with Albinism in Uganda, in which "some local governments in the Busoga subregion have started to include small budget allowances to support persons with albinism, and some of this allowance may be used to purchase sunscreen, although the allowances are not sufficient to meet total needs".[78] The complementary actions of national Governments, local governments, civil society and international organizations could fill the affordability gap.[79]

V. Best practices

70. There are several best practices worth highlighting as effective initiatives in guaranteeing the right to health of persons with albinism. They include innovative initiatives with minimal cost implications, which promise potential for scaling-up and replication.

A. Country strategies

The Fiji Albinism Project

71. The Fiji Albinism Project is an initiative — initially undertaken by civil society that later involved government institutions — which developed a national response to the needs of persons with albinism. The project emerged from the first Fiji Albinism Workshop, held at the Fiji School for the Blind in 2014. The project's steering committee was formed within the Ministry of Health. The project subsequently organized the first Fiji Albinism Awareness Symposium in 2015.

72. Several barriers affecting the lives of persons with albinism in Fiji were identified during the symposium, including: lack of accurate demographic national data on persons with albinism; limited understanding of albinism in the health and education sectors;

[72] Such as in Mwanza, United Republic of Tanzania, as reported by the Mwanza Albino Society.
[73] Committee on Economic, Social and Cultural Rights, general comment No. 14, para. 43.
[74] Ibid., para. 30.
[75] Ibid., para. 43.
[76] A/72/169, para. 19.
[77] General comment No. 14, para. 42.
[78] Ibid.

limited multisectoral communication, and lack of access to services to support persons with albinism and lack of designated funding.[70]

73. As a result, the symposium fostered the implementation of measures to address the health issues of persons with albinism, including awareness at community level, notably to overcome the cultural issues preventing the wearing of hats and sunglasses, as well as through a campaign addressing provincial service officers. Recommendations included increasing awareness at the educational level, granting permission to wear protective clothing and ensuring the application of sunscreens in school settings. Reasonable accommodation was also recommended, including allowing children with albinism to sit at the front of the class with their backs to the windows, mobility around the classroom to improve vision and access to documents with large print.

74. At the national and regional levels, there were recommendations to increase access to health services across the country, through monthly albinism clinics and low-vision clinics. As regards affordability and accessibility, there were recommendations made at the Symposium to investigate the possibility of producing sunscreen locally and distributing it through clinics and schools. In the meantime, as part of the project, monthly skin and eye clinics are organized in Suva.[71] Similarly, there was a suggestion to provide low cost sunglasses through the Fiji Society for the Blind.

75. Finally, the project is governed through multisectoral coordination among the ministries responsible for health, education and women's issues. Modalities of work include the sharing of information, measures to enhance individual care and the appointment of dedicated staff. While the Ministry of Health provides skin and eye clinics, civil society provides free sunscreens and eyeglasses and the Ministry of Education disseminates information on albinism. Today, the main challenges of the project are funding and data collection.[72]

Kenya

76. In 2015, the Government commenced a programme for the purchase and distribution of sunscreen for people with albinism through the National Council for Persons with Disabilities and the Kenya Medical Supplies Authority.[73] In 2016, the Albinism Society of Kenya reported that more than 1,000 persons with albinism had been provided with prescription glasses and other optical devices.[74]

77. High-level stakeholders and leaders in the sector, such as Grace Mumbi Ngugi, Isaac Mwaura and other persons with albinism, convinced the Government to allocate funds for the provision of sunscreen in hospitals, as well as free protective clothing for persons with albinism. As a result, a programme on albinism, with a dedicated officer, was established at the National Council for Persons with Disabilities. Its initial goal was to register persons with albinism so as to plan the allocation of public resources.

78. The programme has been granted significant funding to deliver support to persons with albinism, including the provision of free sunscreen in district hospitals. However, it has been reported that challenges persist, particularly as regards accessibility and the affordability of services. For example, persons with albinism often live far away from district hospitals and free sunscreen is not available to them locally. In addition, it was reported that screening and treatment for skin cancer were not free of charge.[75]

[70] Fiji Albinism Project, "Summarised report" (2015).
[71] Charlene Lawson, "Albinism project", *Fiji Times Online*, 10 August 2016.
[72] Vishaal Kumar, "Albinism project faces big hurdles", *Fiji Times Online*, 15 June 2017.
[73] Under the Same Sun, "Kenyans with albinism and racial discrimination".
[74] See www.albinismsocietyofkenya.org.
[75] Diana Wanguai, "For people with albinism living in Africa, Kenya offers a haven of hope", *Nest* (Kenya), 10 October 2017.

Nigeria

79. In 2012, the Government of Nigeria, under the auspices of its Ministry of Education, adopted a national policy on albinism. The policy outlines the main health challenges faced by persons with albinism, including recommendations on the prevention and treatment of skin cancer.[55] The policy is holistic and covers several areas of work, including the promotion of self-esteem and a feeling of belonging, along with access to health and the promotion of free ophthalmological and dermatological services.

80. To that end, the policy establishes a target, to be achieved by 2020, of a 50 per cent improvement in accessing qualitative and affordable health and social services by persons with albinism. The interventions outlined in the policy will provide basic information and medical services for the prevention of visio-dermal health issues related to albinism; provide counselling and psychosocial services for persons with albinism by health systems stakeholders in public and private sectors; secure free, accessible qualitative treatment and rehabilitation of persons with albinism with skin cancer, sunburn and low vision.

81. The Ministry of Health, in partnership with the National Hospital in Abuja and the Albino Foundation, coordinate a project on free skin cancer treatment, which provides treatments that have a direct impact on avoiding premature deaths. According to the Albino Foundation, free medical treatment has been provided to over 4,000 persons with albinism who have skin cancer.[56] Today, the main challenges of the project are inadequate integration or mainstreaming in the health sector, funding and access to treatment, as the travel costs to Abuja remain prohibitive for most and subsidies by the Albino Foundation in this regard are limited.

United Republic of Tanzania and Malawi

82. In the United Republic of Tanzania and Malawi, the mobile clinics specifically attending to persons with albinism who live in non-urban centres have had a highly positive impact on skin cancer prevention and treatment, as well as reasonable accommodation for visual impairment.

83. In the United Republic of Tanzania, the Regional Dermatology Training Centre at the Kilimanjaro Christian Medical Centre has developed a comprehensive care programme for persons with albinism. The programme includes the registration and periodical health inspection of persons with albinism in different regions of the country; the provision of free dermatological services; education and awareness-raising on the importance of sun protection; and distribution of sun protection materials. In conjunction with Kilimanjaro Sunscreen (KiliSun) and Standing Voice, it covers 10 regions and reaches 2,000 persons with albinism.

84. Furthermore, the programme produces the locally made sunscreen, Kilimanjaro Sun Care or KiliSun, at the Kilimanjaro Sunscreen Production Unit. The unit produces and ensures a free supply of KiliSun, promotes the use of local resources and seeks to avoid reliance on external donations of commercial sun protection products.

85. This production of sunscreen responds to the realities and needs of persons with albinism, following a bottom-up approach. It offers a sun protection factor of at least 30 and protection against ultraviolet A and B radiation. The unit, in collaboration with health workers, community dermatologists and civil society, including the Tanzania Albinism Society and Standing Voice, ensure the quality of distribution, including assessment and education on the use of sunscreen.[57]

86. Moreover, in 2018, the Association of Persons with Albinism in Malawi will launch its first sunscreen pilot production in nine districts, in anticipation of the launch of a full-scale production unit in 2019 or 2020. This initiative is coordinated with the Government, United Nations agencies and KiliSun, and represents direct follow-up to the

[55] National policy on Albinism

[56] See albinofoundation.org

[57] Information received from KiliSun

recommendations of the Independent Expert, which were based on her visit to the country in 2016.

B. Other responses

Technological responses

87. There are specialized institutions and organizations that provide information on technological responses to the challenges posed by albinism, particularly visual aids and sun protection devices. That is important, because such devices, separately or together, may constitute a part of reasonable accommodation for each person with albinism. For instance, the National Organization for Albinism and Hypopigmentation provides regularly updated technical information on low-vision aids, including magnifiers, microscopes and telescopes, non-optical devices and strategies to improve one's vision. Similarly, the National Library of Medicine in the United States of America provides online medical information on albinism, including advice on genetic testing to identify the type of albinism and management of its signs and symptoms, particularly visual impairment and skin protection.

88. In Kuwait, technological services and approaches are applied in all hospitals to ensure complete diagnosis, including physical examinations, descriptions of changes in pigmentation, thorough eye examinations and genetic testing.[89]

Access to surgery and more specialized treatment

89. The type of surgery required for treating visual impairment may include strabismus surgery for either functional (improved peripheral fusion) or cosmetic procedures. Skin cancer treatment, including where there is a slightly enhanced risk of cutaneous melanoma, is not specific to albinism and includes cryogenic treatment, radiotherapy and chemotherapy.[90]

Early intervention measures: registration, counselling and training of nurses and medical staff, particularly in more remote areas

90. Registering persons with albinism at birth represents an important first response to address their health condition. Firstly, it provides the opportunity to inform and counsel the mother and the family about albinism and measures regarding skin protection and managing visual impairment as the child grows. Early information and care increase the prospect of the highest attainable standard of health of persons with albinism. However, records must have adequate safeguards to ensure the right to privacy and to prevent misuse of data for attacks, discrimination or other illicit acts.

91. Many studies confirm the need for awareness-raising and training of nurses and medical staff on albinism, particularly in remote areas. In this regard, good practices have been documented in South Africa in the clinical genetic outreach programme. That programme, which began in 1990, operates as a form of early intervention in the following manner: senior nurses at large rural hospitals, trained in medical genetics, form a network of professionals who identify babies with common genetic disorders at birth and offer immediate support and counselling.[91]

92. Counselling for mothers is essential in overcoming ignorance and misbeliefs about albinism and encouraging acceptance of their children. It also provides advice on the care necessary to prevent skin cancer. Counselling mothers can also prevent infanticide by demystifying the condition of albinism. In that regard, training on albinism for midwives and traditional birth attendants should be prioritized.[92] In addition to counselling, early intervention kits should be made available. For instance, the Kuwait Medical Genetic

[89] Submission of Kuwait.
[90] United States of America, Department of Health and Human Services, National Institutes of Health.
[91] P.M. Lund, "Oculocutaneous albinism in southern Africa", p. 170.
[92] Submission of the Source of the Nile Union of Persons with Albinism.

Centre provides parents with instructions and advice on precautions to help children learn self-care practices.[92]

Reaching circles of persons affected

93. A 2006 epidemiological study on albinism in sub-Saharan Africa, based on a World Health Organization pilot survey, investigated the situation of people with albinism in Africa, estimated that there were tens of thousands of people living with albinism in Africa and called for increased awareness and public health interventions to respond adequately to the medical, psychological and social needs of people with albinism. It recommended that, based on the estimates available and the severity of social issues faced by persons with albinism and their families, there should be a public health response to increase attention on this group of people.[93]

94. It is important to note that the above-mentioned study was conducted in advance of, and therefore without reference to, the violent attacks on persons with albinism, which were first reported internationally in about 2006. It is safe to say that its recommendation to extend support to all those directly affected by albinism has become even more compelling in the light of those attacks, as reports sent to the Independent Expert indicate that family members have also been affected by the attacks, both directly and indirectly. In recognition of the situation, the United Nations Voluntary Fund for Victims of Torture has provided funding to civil society to provide medical, psychological and social assistance support to persons with albinism who are attacked, together with their families.

95. Civil society organizations, such as Standing Voice and Under the Same Sun in the United Republic of Tanzania, are also trying to meet the need to assist family members of persons with albinism by running women's groups across the country. These groups consist of women with albinism and mothers of children with albinism. Various civil society groups globally have also reported doing outreach for the family members of persons with albinism in their ordinary course of work. However, these acts are only a drop in the bucket, as they are often ad hoc and not systemized, and therefore have limited reach.

VI. Conclusion and recommendations

96. **The main health issues faced by persons with albinism, namely visual impairment, high susceptibility to skin cancer and misbeliefs about the condition of albinism, have been known for more than half a century. Today, responses to those issues are mainly led by the tireless work of nascent organizations of persons with albinism and other civil society organizations, and are supported by research in this area. Nevertheless, those measures still need to be mainstreamed in health policies and strategies worldwide.**

97. **Accordingly, the Independent Expert recommends that Member States, particularly those in which there are records of attacks and in which the issue has been left out of mainstream health policies:**

General measures

(a) **Address health-related aspects of albinism as a public health concern;**

(b) **Ensure the adoption of special measures on persons with albinism in policies governing health and disabilities, as well as the training curricula of health-related professions.**

[92] Submission of Kuwait.

[93] Esther S. Hong, Hajo Zeeb and Michael H. Repacholi, "Albinism in Africa as a public health issue", *BMC Public Health*, vol. 6 (2006). Available at www.ncbi.nlm.nih.gov/pmc/articles/PMC1584235.

98. In this regard, the Independent Expert also recommends that member States:

(a) Include specific services for persons with albinism in existing health centres;

(b) Provide guidance for health professionals on the care needed by persons with albinism and ensure that the training of health workers, including ophthalmologists, dermatologists and nurses, includes topics on the condition of albinism and protective measures;

(c) Ensure that albinism is included in early intervention programmes on health, including dissemination of detailed health-care information and advice;

(d) Develop specific, concrete and time-bound national action plans on albinism;

(e) Ensure the prompt provision of medical and psychological support to the victims of attacks and their families;

(f) Ensure that the right to the highest attainable standard of health is exercised without discrimination of any kind, in particular against persons with albinism;

(g) Adopt special measures, if necessary, to guarantee equal access to health care for persons with albinism. Such measures should be based on statistical data and supported by adequate funding;

(h) Gather data systematically on persons with albinism, including when collecting data on health or disabilities, and by inserting a specific question on albinism in questionnaires when conducting population censuses;

(i) Adopt public health policies to address issues affecting persons with albinism, ensuring their full participation in the process of elaborating such policies and in awareness-raising action on such policies;

(j) Ensure that measures regarding the right to health of persons with albinism are the responsibility of the institution in charge of the issue, such as the ministry responsible for health;

(k) Ensure that the institution in charge of the issue, such as the ministry of health, carries out its mission in coordination with other relevant institutions, such as those in charge of disabilities, education, labour and social protection, as well as those with responsibility for women and children's rights.

99. Concerning skin cancer and visual impairment, the Independent Expert recommends that member States:

(a) Include sunscreen on the list of essential medicines without further delay;

(b) Ensure the availability, accessibility, affordability and quality of treatment for skin cancer without discrimination. Such treatment should include curative measures, as well as cosmetic treatment to restore or improve appearance to avoid further discrimination based on appearance;

(c) Deliver accessible and culturally appropriate rehabilitation programmes, particularly concerning skin cancer and visual impairment;

(d) Support or initiate the production and distribution of locally produced sunscreen, such as KiliSun. Distribution should include health education on the use of such a product;

(e) Support best practices, such as mobile clinics where they exist or initiate such measures;

(f) Ensure that specific measures for persons with albinism are integrated into disability-related programmes, including the distribution of vision devices as a means of reasonable accommodation;

(g) **Facilitate the importation of glasses and gadgets as a measure of reasonable accommodation, for example, by removing taxes and administrative costs associated with the importation of these goods.**

100. **With regard to exogenous conditions affecting the enjoyment of the right to the highest standard of physical and mental health, the Independent Expert reiterates her previous recommendations that member States, particularly those in which there are records of attacks:**

(a) **Conduct in-depth research on the root causes of attacks against persons with albinism, including on harmful practices related to witchcraft;**

(b) **Develop and implement long-lasting awareness-raising campaigns, as they are critical in addressing the harmful practices and rampant myths affecting the enjoyment of human rights by persons with albinism;**

(c) **Review and adapt legal frameworks, as needed, to ensure that they encompass all aspects of the attacks against persons with albinism, including with regard to the trafficking of body parts;**

(d) **Regulate the practice of traditional medicine, including through mechanisms such as Government-led licensing and monitoring regimes in both urban and rural areas, and establish adequate standards for traditional medicine;**

(e) **Ensure that social services are accessible to persons with albinism without discrimination and with reasonable accommodation, in particular in a manner that does not subject them to further stigmatization or require them to be exposed to the sun in order to receive support from social services;**

(f) **Cooperate with civil society organizations that provide support to persons with albinism and their families.**

101. **The Independent Expert recommends that civil society and Governments should, in the course of their work and in collaboration:**

(a) **Continue to conduct quality research to shape public policy and effectively implement sun protection strategies;**

(b) **Support prevalence and epidemiological studies as a basis for developing effective measures;**

(c) **Publish data acquired in the course of their work to inform collaborative work and develop policies and adequate measures;**

(d) **Continue to raise awareness to:**

(i) **Include specific information on albinism and, in particular, susceptibility to skin cancer in training for health professionals;**

(ii) **Ensure that there is no barrier to the recognition of persons with albinism as persons with disability;**

(iii) **Use international albinism awareness day as an opportunity to inform the general public about albinism and, whenever appropriate, engage in media campaigns to this effect.**

102. **The Independent Expert recommends that the World Health Organization, in response to recommendations made in the epidemiological study on albinism, pursue or facilitate government action to ensure that albinism is taken up as a public health concern, particularly where there are attacks and/or where there has been historical neglect to the detriment of the enjoyment of human rights by persons with albinism.**

103. **The Independent Expert recommends that the international community, including international organizations:**

(a) **Support efforts for the realization of the right to health of persons with albinism, such as the scaling-up of best practices identified in the present report, and by ensuring its insertion into existing health projects;**

(b) **Support epidemiological studies on albinism in order to gather the data necessary to develop public health policies;**

(c) **Ensure that, in particular in regions affected by attacks, actions designed to guarantee the right of persons with albinism to the highest attainable standard of health are incorporated into existing health projects and programmes of general scope and that, in addition, specific programmes are designed and given priority.**

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Report of the Independent Expert on the enjoyment of human rights by persons with albinism on her mission to the United Republic of Tanzania

Note by the Secretariat

The report of the Independent Expert, which draws on the information she gathered during her visit, focuses on the challenges that must still be addressed to lower the number of reported attacks against persons with albinism in the United Republic of Tanzania. The Independent Expert also discusses other aspects of the situation, such as discrimination against persons with albinism, particularly in the areas of health and education, as well as the situation of persons with albinism living in designated schools. She highlights the important steps taken by the Government to address these issues and makes recommendations for strengthened efforts, including by addressing implementation gaps and removing barriers to the enjoyment of human rights by Tanzanians with albinism.

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Report of the Independent Expert on the enjoyment of human rights by persons with albinism on her mission to the United Republic of Tanzania*

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* Circulated in the language of submission only.

I. Introduction

1. In accordance with the mandate set out in Human Rights Council resolution 28/6 and at the invitation of the Government of the United Republic of Tanzania, the Independent Expert on the enjoyment of human rights by persons with albinism, Ikponwosa Ero, conducted an official visit to the United Republic of Tanzania from 18 to 28 July 2017. The objective of the visit was to assess the human rights situation of persons with albinism throughout the country, with particular attention to be given to the relatively high number of reports of attacks against them.

2. During her visit, the Independent Expert travelled to the cities of Dodoma, Dar es Salaam, Mwanza, Shinyanga, Kigoma and Kasulu. She met with the Speaker of the National Assembly, the Attorney General, the Deputy Minister in the Office of the Prime Minister responsible for policy, parliamentary affairs and matters involving labour, employment, youth and persons with disabilities, the Chair of the Commission for Human Rights and Good Governance and representatives of the Ministry of Education, Science, Technology and Vocational Training, the Ministry of Health, Community Development, Gender and Children, the Ministry of Constitutional Affairs and Justice, the Ministry of Finance and Planning, the Ministry of Foreign Affairs and East African Cooperation, the President's Office for Regional Administration and Local Government, the National Bureau of Statistics and the Tanzania Police Force, including community police. She also met with officials from the municipalities of Shinyanga and Kigoma and head teachers and staff members of schools designated as shelters, including Buhangija and Lake View — both in Mwanza — and Kabanga in Kasulu.

3. In addition, the Independent Expert met with academics and civil society organizations, particularly those representing persons with albinism, such as the Tanzania Albinism Society. Most importantly, she visited numerous persons with albinism, including victims of attacks, to hear from them about their enjoyment of their human rights. She also met with the United Nations country team and the heads of cooperation and foreign missions resident in the United Republic of Tanzania and active in the donor community. She observed the provision of health services to persons with albinism by civil society and government institutions in Mwanza and at Ocean Road Cancer Institute in Dar es Salaam.

4. The Independent Expert is grateful to the Government of the United Republic of Tanzania for its cooperation. In particular, she notes that her visit was the first official visit by a special procedure mandate holder that the country had agreed to in nine years. She is also grateful to all her interlocutors, especially persons with albinism, who shared their collective experience and individual perspectives with her. She looks forward to fruitful and continued dialogue with the Government and other stakeholders on the implementation of the recommendations contained in the present report.

5. The Independent Expert thanks the United Nations country team, particularly the Office of the Resident Coordinator and the United Nations Educational, Scientific and Cultural Organization (UNESCO), for their effective logistical, administrative and substantive support. She would also like to thank the Ministry of Foreign Affairs and East African Cooperation for coordinating all official meetings.

II. Background

A. General overview

6. The United Republic of Tanzania was formed as a sovereign State in 1964 through the union of the States of Tanganyika and Zanzibar. The country is composed of the Mainland — the vast majority of the territory — and Zanzibar. United Republic of Tanzania, which has autonomy over non-union matters in the archipelago. In 1974, Dodoma was designated the official capital of the country. However, it shares the seat of government and administrative offices with Dar es Salaam.

7. In October 2015, John Pombe Magufuli was elected the fifth President of the United Republic of Tanzania. The executive branch of the Government comprises the President, the Vice-President, the President of Zanzibar, the Prime Minister and the Cabinet.

8. The United Republic of Tanzania is bordered by Kenya and Uganda to the north, Rwanda, Burundi and the Democratic Republic of the Congo to the west, Zambia, Malawi and Mozambique to the south and the Indian Ocean to the east. Attacks against persons with albinism have been reported in all countries bordering the United Republic of Tanzania.[1]

9. Political stability has provided a solid foundation for growth (averaging 6 to 7 per cent a year) in the past decade, according to an overview of the country published by the World Bank.[2] Despite this growth, however, reducing poverty and maternal mortality is still a major challenge, as the social and economic dividends of the country's growth have not reached the majority of the population. Key challenges identified in the United Nations Development Assistance Plan (2016–2021) included the need to improve the quality and scale of health care, education and other social services to cope with rapid population growth, the need to reach marginalized groups and the need to address a number of governance issues, including the protection of vulnerable groups.

10. Government efforts to increase tax receipts, including by eliminating exemptions, curbing evasion and combating corruption, have enabled ongoing public investment. According to the Tanzanian anti-corruption agency, however, corruption is still prevalent, and the efforts made to combat it are not entirely sufficient.[3] A special court with jurisdiction over cases of alleged corruption (the Corruption and Economic Crimes Division of the High Court) was established in September 2016.

11. In addition, according to the Office of the United Nations High Commissioner for Refugees, there are 198,000 registered refugees, many from Burundi and the Democratic Republic of the Congo, residing in the United Republic of Tanzania.

B. Persons with albinism

12. Although there are people with albinism throughout the world, the impact of the condition on human rights and the way it is perceived by others, including its effect on social inclusion, vary from region to region. Albinism is non-contagious, genetically inherited and affects people regardless of race, ethnicity or gender. It results from a significant deficit in the production of melanin and is characterized by the partial or complete absence of pigment in any part or all of the skin, hair and eyes. Persons with albinism therefore often appear pale in comparison to members of their family and their communities. Today, it is estimated that in Europe and North America there is one case of albinism for every 17,000 to 20,000 births. In sub-Saharan Africa, the reported frequency ranges from 1 in 5,000 to 1 in 15,000 births, with prevalence rates of 1 in 1,000 for selected populations. A higher frequency has been reported in parts of the Pacific (1 in 700) and among some indigenous peoples in North and South America (1 in 70 to 1 in 125).

13. There are different types of albinism. The best-known type is oculocutaneous albinism, which affects the skin, hair and eyes. Within this type are subtypes that may reflect varying degrees of melanin deficiency. A lack of melanin in the eyes results in high sensitivity to bright light and significant vision impairment, with the level of severity varying from one person to another. This vision impairment often cannot be completely corrected. In addition, one of the most serious health implications of albinism is vulnerability to skin cancer, which is still a life-threatening condition for most persons with albinism in certain regions. All violations of civil and political rights relating to albinism

[1] Information on those attacks is available from www.underthesamesun.com/sites/default/files/Attacks%20of%20PWA%20-%20extended%20version.pdf.

[2] Available from www.worldbank.org/en/country/tanzania/overview.

[3] Home-grown national corruption and anti-corruption indicators: final report (August 2016), p. vi.

reported to date have been linked to its oculocutaneous form, which is also the most visible form.

14. Under international human rights law, persons with albinism enjoy normative protection covering all their fundamental human rights, including the right to life, physical integrity, liberty and security, the right to the highest attainable standard of physical and mental health and the right to an adequate standard of living. Further protection is afforded by the Convention on the Rights of Persons with Disabilities and the International Convention on the Elimination of All Forms of Racial Discrimination, which proscribes "racial discrimination" on the basis of colour.

15. According to the National Bureau of Statistics, the population of the United Republic of Tanzania, as ascertained by the country's most recent census, in 2012, was 44.9 million, including 16,477 people with albinism.[4] In 2017, the population of persons with albinism was estimated to be around 18,000. However, both Tanzanians with albinism and the Government agree that those numbers are likely to be well under the reality, given the practical and methodological limitations of the census. The remotest areas could not be reached, and it was reported that some persons with albinism may have been hidden by their families when the census was conducted. In addition, a number of persons with albinism interviewed reported not being counted or interviewed at the time of the census. The Independent Expert also received information regarding the significant disparities between census figures for males with albinism (1 in 2,341 nationally and 1 in 2,558 for the group aged 0 to 19 years) and those for females with albinism (1 in 3,032 nationally and 1 in 3,900 for the group aged 0 to 19 years). Although the disparities could be linked to flaws in data collection, they merit further study.

16. The Independent Expert commends the fact that the census included a specific category for albinism, separate from other categories, such as visual impairments. The inclusion of that census category is a best practice in the region. The data from the 2012 population and housing census thus allowed the National Bureau of Statistics to draw conclusions on albinism in its Disability Monograph, published in 2016, which analyses and provides information on albinism and difficulties in such domains as seeing, hearing, walking, remembering and self-care.

17. Recognizing the need for comprehensive data, the Government, in cooperation with the Tanzania Albinism Society, is planning to collect data based on existing administrative records. Although it may not be possible to reach the remotest areas, and although many persons with albinism, given the stigma they must deal with and the poverty and exclusion that are often their lot, may not have administrative records, it is important to complement existing data and ensure that they are disaggregated to fully understand the situation of the human rights of persons with albinism.

18. The Independent Expert is acutely aware of the sensitive nature of information and data regarding persons with albinism, in particular where such information may reveal their whereabouts, and calls for high standards of data protection in this regard.

III. Legal and institutional framework

A. Legal framework and policies

19. The United Republic of Tanzania ratified the International Covenant on Civil and Political Rights and the International Covenant on Economic, and Social and Cultural Rights in 1976. It ratified the Convention on the Rights of Persons with Disabilities in 2009, the International Convention on the Elimination of All Forms of Racial Discrimination in 1972, the Convention on the Rights of the Child in 1991 and the Convention on the Elimination of All Forms of Discrimination against Women in 1985.

[4] Population and housing census report of 2012.

20. The country has yet to ratify the Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment. In addition, the Independent Expert notes that, although the United Republic of Tanzania has ratified the Convention on the Rights of Persons with Disabilities, it has not yet submitted its initial report on its efforts to implement the Convention to the relevant Committee. The Attorney General's Office has expressed its intention to finalize the report shortly.

Attacks

21. Although the country does not have specific legislation on attacks against persons with albinism, its legislative framework includes a number of relevant provisions.

22. The provisions of the Penal Code addressing murder, assault and grievous bodily harm, attempted murder, abduction, conspiracy to murder and kidnapping, for example, have been used to prosecute persons responsible for attacks against persons with albinism. Article 128 of the Code can also be invoked, as it criminalizes disinterring, dissecting or causing damage to the dead body of any person. The Attorney General's Office has also prosecuted persons found in possession of body parts.

23. The Anti-Trafficking in Persons Act (2008) and its regulations adopted in July 2015 protect Tanzanians from any threat of violence and exploitation and seek to eliminate trafficking in persons, including for the purpose of organ removal. Article 3 of the Act states that "organs" include any part of the human body that can be removed and used to sustain life or for any purpose. The trafficking of body parts for muti or juju could thus be covered by the Act. However, although the provisions of the Act would apply in the event that a person was moved by abduction, coercion or deception for the end goal of organ removal, they would not apply to the trafficking of body parts that were harvested from a victim who was not moved, as is often the case with persons with albinism. In other words, persons caught with body parts from a person with albinism murdered but not moved could not be charged under the Act.

24. The Law of the Child Act (2009) is also important, as the majority of persons with albinism who are victims of attacks in the United Republic of Tanzania are reportedly children. The Act seeks to protect children by incorporating elements essential to the development of a protective environment, including a child-protection framework to prevent and respond to abuse, violence, exploitation and neglect. It also seeks to implement a child-friendly justice system.

25. The Witchcraft Act, although outdated, contains criminal provisions addressing the practice of witchcraft, which is a root cause of the attacks. The Act provides for the punishment of anyone who purports to have the power of witchcraft, makes, uses or has in his or her possession any instruments of witchcraft, supplies to any other person any instrument of witchcraft, advises any other person upon the use of witchcraft or any instrument of witchcraft or threatens to use or resorts to the use of witchcraft. "Instruments of witchcraft" are defined broadly and would probably include anything generally believed to contain witchcraft potencies, including charms and medicines. The definition is therefore likely to encompass the possession of body parts of persons with albinism.

26. However, the Witchcraft Act raises many concerns, including in respect of the definition of "witchcraft", which remains elusive in the Act. It also poses challenges as to what is admissible as evidence of such practices in judicial procedures. In 1997, a presidential commission observed that the Act remained entrenched in colonial jurisprudence and should be repealed.[7]

27. As in many other countries in the region, it is very difficult to differentiate the work of witchcraft practitioners or witch doctors from that of traditional healers. In response to this problem, the Government adopted the Traditional and Alternative Medicines Act (2002). One of the purposes of the Act was to regulate practitioners of alternative medicine who had formal training and healers who provided traditional remedies using plants, animal and mineral substances and the like. The Act, under which the Traditional and Alternative

[7] The Nyalali Commission, which submitted its report on 17 February 1997.

Health Practice Council, a regulatory body, was established, prohibits the practice of unregistered persons and establishes the duties of practitioners towards their patients.

28. This approach is to be commended, as it involves oversight of the practices of traditional healers and distinguishes between registered practices and illegal ones. However, the Independent Expert notes that full implementation of this Act requires ongoing efforts and resources for regular checks and permanent oversight. According to information received from a number of sources, only a minority of traditional and alternative health practitioners are registered, and in remote areas in particular, including where attacks against persons with albinism have been reported, there is still confusion about what is a legitimate practice and what is not.

29. A review of the Witchcraft Act and the Traditional and Alternative Medicines Act was to be carried out as part of the National Human Rights Action Plan (2013–2017), which is coming to an end. As the review has yet to be conducted, the Attorney General's Office stressed that it would be included in the second National Human Rights Action Plan (2018–2022).

Persons with disabilities

30. The Persons with Disabilities Act (2010) was adopted to give legal effect to the National Policy on Disability (2004) and implement the provisions of the Convention on the Rights of Persons with Disabilities. The Act requires the Government to take appropriate steps to ensure that persons with disabilities have full enjoyment of their rights and freedoms, without discrimination. It addresses health care, education, rehabilitation, employment, accessibility, participation, integration, non-discrimination and other relevant matters.

31. The division of the Prime Minister's Office responsible for, inter alia, disability affairs has indicated that it intends to review both the National Policy on Disability (2004) and the Persons with Disabilities Act (2010) and develop a national action plan on the promotion of the rights of persons with disabilities.

32. Furthermore, the Ministry of Health, Community Development, Gender and Children is in the process of developing the national guidelines on health-care fee waivers for persons with disabilities to facilitate access to health care for such persons, including persons with albinism.

33. In addition, in follow-up to its inclusive education policy, the United Republic of Tanzania developed the National Strategy on Inclusive Education (2009–2017) and formulated guidelines on support services for children with albinism and visual impairments. Although these are excellent steps towards the full realization of the right to education of persons with albinism, further measures are necessary to implement this policy throughout the country.

B. Institutional framework

Albinism

34. The Deputy Minister responsible for labour, youth, employment and disability affairs, who works from the Prime Minister's Office, has a mandate to ensure the realization of the human rights of persons with albinism.

35. The 2015 appointment of a person with albinism to this position was widely applauded. It led to the necessary prioritization of the issue and fruitful initiatives advancing the promotion and protection of the rights of persons with albinism. Of particular note were the Deputy Minister's efforts to begin reintegrating those who had been displaced by attacks.

36. Unfortunately, the prioritization of the human rights of persons with albinism seems to have been linked more closely to the Deputy Minister's personal experience than to the pursuit of any long-term policy by the Prime Minister's Office. Moreover, with the recent reassignment of the former Deputy Minister to other functions abroad, it appears that

matters related to albinism, now dealt with mainly by the Directorate responsible for disability affairs, are not a priority of the current Deputy Minister. The Independent Expert is of the view that this change has affected the visibility and prioritization of the issue.

37. In response to the violence and inherent criminality of attacks against persons with albinism, committees were established at the ministerial level — at the Ministry of Home Affairs, for example — with a view to ensuring the protection of persons with albinism.

38. In November 2016, the Deputy Prime Minister's Office convened a task force, thereby leading to the de facto replacement of those committees. The task force, which seeks to take a coordinated approach to issues relating to persons with albinism, comprises representatives of the Government, civil society organizations and United Nations agencies. It is chaired by the Deputy Prime Minister's Office, while UNESCO acts as the secretariat. It has used a multisectoral approach to develop a detailed and promising strategy to ensure the protection and well-being of persons with albinism in the United Republic of Tanzania. The Independent Expert welcomes the establishment of this task force, which has effectively synthesized the work of previous committees working on the issue. Moreover, the task force's strategic plan effectively mirrors the Regional Action Plan on Albinism in Africa (2017–2021), a plan promoted by the Independent Expert and recently endorsed in a resolution adopted by the African Commission on Human and Peoples' Rights.[8] Furthermore, the strategic plan provides a solid framework for consolidating the gains attained to date through a multi-stakeholder approach led by the Government.

Persons with disabilities

39. The National Advisory Council for Persons with Disabilities was established by the Persons with Disabilities Act (2010) to monitor and ensure the implementation of the rights of persons with disabilities. It is chaired by the Office of the Prime Minister responsible for policy, parliamentary affairs and matters involving labour, employment, youth and persons with disabilities. However, it was stressed that resources for the Council's full functioning are still lacking.

40. To implement the Persons with Disabilities Act, the Prime Minister's Office, through the President's Office on Regional Administration and Local Government, has issued a circular to establish disability committees at the village, ward, district and regional levels. These committees are to be involved in data collection and reporting on issues — both opportunities and challenges — affecting persons with disabilities, including persons with albinism.

41. The Independent Expert was also informed that the National Fund for Persons with Disabilities, created by the Persons with Disabilities Act, would be set up in 2018 and that Parliament had allocated specific funds to that effect. The Fund will be used to support education and vocational training, rehabilitation programmes and research. It will also issue grants to civil society organizations.

Law enforcement

42. The Attorney General's Office provides legal advice and drafting services to the Government. Through its Directorate of Public Prosecutions, it conducts prosecutions and coordinates the investigation of all criminal cases. In 2009, the Directorate took steps to address the attacks on and killings of persons with albinism by assigning such cases to a unit responsible for gender affairs and vulnerable groups.

43. The measures taken by the country to respond to attacks on persons with albinism included the placement of specialized personnel in the department responsible for offences against persons and trafficking-related offences at police headquarters and in its subordinate units. Standing operational task forces with specialized law enforcement personnel were deployed at the peak of the crisis to focus on crimes against persons with albinism.

[8] Available from www.achpr.org/sessions/60th/resolutions/373.

44. Community policing started in 2006; each of the country's 3,633 wards has a community police officer. Community police officers work closely with village leaders, traditional authorities, religious leaders, teachers and traditional healers. They ensure that village security committees, which set local priorities, are effective. A number of security committees have identified attacks against persons with albinism as a particular concern.

Centres and schools used as shelters

45. As a provisional, emergency response to the surge of attacks, the Government referred children with albinism to primary schools with boarding facilities, which were to be used as temporary shelters to ensure their safety. In 2015, the Government intensified its efforts to refer children with albinism to these shelters.

46. Although the emergency that triggered the creation of these shelters appears to have become less acute, the shelters are still being used, and persons with albinism were reportedly still being brought to them for protection (although the number of these arrivals is far less than at the peak of the attacks between 2008 and 2010). Civil society organizations informed the Independent Expert that there were more than 32 known schools and other facilities used as shelters in the country. If the needs of persons with albinism are to be met, it is fundamental for the Government to ensure the collection of accurate and comprehensive data on the whereabouts of displaced persons with albinism and share them with other stakeholders providing services to such persons.

National Assembly

47. The National Assembly, as constituted in 2015, has 390 members. They include 263 Members of Parliament, elected to represent constituencies across the Mainland and Zanzibar, 113 special seats for women members, 5 members elected by the Zanzibar House of Representatives from among its members, the Attorney General and 8 members appointed by the President. In 2008, using his prerogative, the President nominated Alshaymaa Kwegyir as the first Member of Parliament with albinism. She served two full terms. Regrettably, the Parliament no longer has a member with albinism appointed under this presidential prerogative.

Health

48. The Regional Dermatology Training Centre, in the municipality of Moshi, was created in partnership with the Tanzanian Ministry of Health, Community Development, Gender and Children to provide dermatological services, including through training for medical professionals and clinicians from the country and the subregion. Its skin cancer prevention and treatment services are provided regularly to persons with albinism. In addition, the Centre runs mobile clinics periodically, mainly in the north of the United Republic of Tanzania.

49. One of the main partners of the Centre's mobile operations is the non-governmental organization (NGO) Standing Voice. Its mobile skin-care clinics bring dermatologists to 33 sites in eight regions of the country every six months. The programme consists of an awareness-raising component, a full screening for precancerous lesions on persons with albinism, cryogenic treatment where necessary, the distribution of sun hats and sunscreen and referrals for surgery. Clinic outreach is carried out with the support of the Tanzania Albinism Society, and the Centre's dermatologists provide treatment. Memorandums of understanding signed with local schools and hospitals ensure that mobile clinics come to the same premises every six months. This model prevents many early deaths from skin cancer — which reportedly kills most persons with albinism in the United Republic of Tanzania before they reach the age of 40[7] — and the Independent Expert encourages expanding the model to the entire country, with greater support from the Government.

[7] Geraldine R. McBride, "Oculocutaneous albinism: an African perspective", *British and Irish Orthoptic Journal*, vol. 11 (2014), p. 11.

50. The sunscreen distributed through mobile clinics, KiliSun, is the first of its kind in the region. It is locally made and formulated for general use with specific attention to the needs of persons with albinism. Local production is particularly important, as it ensures constant availability of an item that is a basic necessity for persons with albinism. It avoids the cost and delays associated with imports and ensures that the sunscreen is distributed well before its expiry date, which is not always the case with imported sunscreen.

51. Treatment for skin cancer is provided in a limited number of hospitals and clinics. In all, two centres are equipped for radiotherapy and four for chemotherapy. Ocean Road Cancer Institute, where the offices of the Tanzania Albinism Society are located, provides both services.

IV. Main findings and challenges

A. Attacks

Context

52. Violence, including physical attacks against persons with albinism in the United Republic of Tanzania, began receiving national attention in 2006 and international attention the following year. The seriousness of those attacks, many of which led to death, mutilation and displacement, prompted national initiatives from the Government, civil society and international actors. According to data provided by the Attorney General's Office, 66 cases of attacks against persons with albinism had been reported at the time of the visit of the Independent Expert. Fifty-five of those cases, it was reported, had led to court proceedings, while 11 were still under investigation. Civil society disputes those numbers, providing a much higher aggregate figure and reiterating that these are reported cases alone. All records — both government and civil society — show that the regions of Mwanza, Kagera and Geita are particularly affected by violence.

53. In 2015, joint supervision missions were conducted in eight regions of the Lake Zone (Tabora, Shinyanga, Simiyu, Geita, Mwanza, Kagera, Mara and Kigoma) with a high number of reported attacks. The Directorate of Public Prosecutions, the Police Force and the NGO Under the Same Sun took part in these missions to compare the data they had received. The objective of the missions was to harmonize data, identify cases of attacks against persons with albinism, obtain accurate records and determine the challenges to investigating and prosecuting cases. Such joint missions are a positive example of cooperation between the authorities and civil society and should continue, not only to address data discrepancies but also to step up cooperative efforts to eradicate the problem and its root causes.

54. The Independent Expert was informed by persons with albinism that a number of cases of targeted violence and attacks had not been reported to the authorities. The reasons for not reporting such cases through official channels included the victim's preference for reporting to civil society, the growing sense of national shame around the attacks and a corresponding unwillingness to report the crimes in the media and the difficulty of reporting attacks from remote areas, despite the work of the community police. In addition, some cases are unlikely to be reported either to officials or to civil society because of a lack of awareness of these avenues and other circumstances, such as the involvement in the crime of a parent or other family members.

55. Data provided by the Attorney General's Office suggest that the focus has been on grave offences such as murder and assault (41 cases) or grievous bodily harm (13 cases). Since 2006, only one case of a person being found in possession of body parts has been recorded, despite the nature of these crimes, which often involve the harvesting and trafficking of body parts. Other cases included one exhumation of a body, one kidnapping, two conspiracies to commit murder, two abductions, two instances of human trafficking and five attempted murders. These data contrast with information recorded by civil society and reported by persons with albinism.

56. Information received from both the Government and civil society confirm a decrease in the number of reported attacks. However, the Independent Expert also received information stressing that it had recently become more complicated to publicly report and denounce such cases, in particular through the press, social media or documentaries. The Independent Expert notes that to fully comprehend the situation of persons with albinism and the extent of the reduction in the number of attacks, it is important to facilitate the reporting of cases through all channels and to continue encouraging the law enforcement authorities to respond proactively.

57. Furthermore, the Independent Expert stresses the importance of collecting data on the security of persons with albinism and of information sharing between civil society and the Government. This should include information gathered from relatives of victims as well as witnesses to human rights violations both within and outside temporary shelters. Replicating past examples of data sharing and initiatives to harmonize information, such as joint missions of diverse stakeholders, including the Government and civil society, can help fill this gap.

Law enforcement and prosecution

58. The reported decrease in the number of attacks was achieved in part through measures put in place by the Government and other actors. The measures included the prioritization of investigation and prosecution of attacks against persons with albinism, the use of standing task forces with specialized law enforcement training at the peak of the attacks and major awareness-raising programmes. Those efforts were part of a timely response that enhanced deterrence.

59. However, persons with albinism, including survivors of attacks and families of victims, appeared to be largely unaware of the status of relevant investigations and prosecutions. They were also unaware of how or whether those found guilty of attacks were sentenced. This lack of information on judicial proceedings has a detrimental effect on the reporting of cases to authorities. Developing channels to enhance the flow of information is important to enhance deterrence. It is also important to ensure that victims and their families have access to relevant information and to prevent mob justice at the community level, which is often the result of perceived inaction or insufficient action by the State.

60. In this regard, the Tanzania Albinism Society, which has a wide network at the local level, and other civil society organizations, should be given greater support for their efforts to keep victims and their families informed of the outcomes of cases involving attacks on persons with albinism.

61. Strategies for upholding the human rights of persons with albinism must be firmly grounded in international human rights law. The Independent Expert notes that there are calls for the implementation of the death penalty for crimes against persons with albinism. On this matter, the Independent Expert stands with the Secretary-General in affirming that the death penalty has no place in the twenty-first century. This is especially the case where — as in these cases — investigations are challenging.

62. Challenges in investigation, as identified by the Attorney General's Office, include a lack of adequate and reliable information, deep-rooted beliefs in witchcraft and the remote and isolated locations where attacks have occurred.

63. The judicious use of multiple pieces of legislation is likely to strengthen the legislative framework in cases of attacks against persons with albinism. They include the Penal Code, the Anti-Trafficking in Persons Act (2008) and the Law of the Child Act (2009). The provisions of the Penal Code on possession of body parts, for example, are fundamental to combating trafficking of body parts. The Independent Expert notes, however, that they have not yet been invoked for that purpose.

64. Similarly, in investigating and prosecuting crimes against persons with albinism, greater emphasis should be given to identifying the criminal masterminds, organizers, criminal customers, the end users of body parts and the witch doctors involved. According to reports, there are no cases where the mastermind was prosecuted. The dissemination of information on prosecuted masterminds would significantly enhance deterrence.

65. Furthermore, some of these crimes involve a cross-border element, such as trafficking in persons and in body parts, that complicates investigation. In places such as Kibondo, a district that shares a border with Burundi, regular meetings are being held between the police of both countries, at the local level, to facilitate cross-border police cooperation. Consular authorities in Kibondo are also involved in facilitating cooperation. While these are positive steps, they should be complemented by a clear police cooperation agreement between the United Republic of Tanzania and its neighbouring countries, and relevant international organizations should be involved. The development of a subregional plan on trafficking, an ongoing process being promoted by the International Organization for Migration and the United Nations Children's Fund (UNICEF), could also facilitate international cooperation in this regard.

Persons with albinism in refugee camps

66. Persons with albinism living in refugee camps in the United Republic of Tanzania can also find themselves living in precarious situations. In situations of forced displacement, persons with albinism face particular protection risks, especially in regions where myths about albinism are rampant. The distress of displacement, coupled with the destruction of trusted social networks, is among the many factors that can aggravate the insecurity of displaced persons and refugees with albinism.

67. In Kasulu, such security concerns were brought by families of children with albinism to the police. As a result, those families were relocated to areas in close proximity to the police unit of the refugee camp.

Support for victims

68. Support for victims of attacks and their families, including legal, medical, psychosocial and socioeconomic support, is fundamental to enabling them to rebuild their lives and restore their dignity. The Government has provided a certain amount of medical and material support to some victims of attacks, and this is to be commended. In the provision of such support, however, the security needs of persons with albinism should be given all due consideration, and the measures taken in that regard should be grounded in legal and international standards regarding redress for victims.

B. Root causes

69. Although the safety of persons with albinism appears to have increased in recent years, the situation remains very precarious. Not only do the attacks continue — albeit less frequently — but the root causes thereof are also still present. Fear persists in various regions of the country, driving persons with albinism and/or their families to continue to seek protection in shelters. In addition, persons with albinism living in shelters often fear returning to their villages, given the widespread belief in witchcraft, the persistence of myths and the disproportionate levels of poverty they face.

70. Commendable measures have been taken by the Government to address witchcraft, including the registration of traditional healers to differentiate their practices from those of witch doctors. However, only a small number of traditional healers have registered, and the confusion persists, particularly in rural and remote areas. Putting an end to that confusion is a long-term process that requires specific measures, such as dispelling myths about persons with albinism and increasing awareness of the differences between traditional medicine and witchcraft. The participation of registered traditional healers in awareness-raising activities would be particularly effective in dispelling confusion. In addition, the current review of the Witchcraft Act provides an opportunity to address the issue.

71. Deep-seated myths about persons with albinism, including the belief that they do not die but disappear or that their body parts have special powers when used in rituals and concoctions prepared by witchcraft practitioners, remain widespread. These myths are at the root of attacks against persons with albinism. They have also led to the abandonment of children with albinism and the rejection of parents of children with albinism by their families or communities. Furthermore, the hypervisibility and colouring of persons with

albinism, along with the lesions that skin cancer often leaves on their skin, combined with a lack of general education on albinism, contribute to and strengthen the myths dehumanizing persons with albinism.

72. As long as such myths persist, the risk of a resurgence of attacks remains present. Intensive, long-term awareness-raising in all national languages and reaching all areas, particularly rural and border areas, is necessary. It will require joint efforts by all stakeholders, including the authorities, persons with albinism, local leaders, traditional healers and faith-based organizations.

73. A good example of such awareness-raising was a pilot project carried out by UNESCO in 2015–2016 on community sensitization. The project made use of community radio stations and took a sociocultural approach by empowering key community stakeholders and family members of persons with albinism to mobilize their communities to protect and promote the well-being and rights of persons with albinism. The project's success in changing mindsets is a strong indicator that similar preventive and protective efforts are required immediately and for the longer term.

C. Centres and schools used as shelters

74. To protect persons with albinism, particularly as the number of reported attacks peaked, schools and similar centres were used as temporary shelters. This measure probably contributed to the decrease in the number of attacks, as there have been no reported cases from these shelters. Moreover, as the measure does not address the root causes of the attacks, the schools and other such centres used as temporary shelters are bound to become permanent.

75. Many persons with albinism living in the shelters do not feel safe outside and are afraid of going back to their villages on a long-term basis, as the risk of attacks remains high. Moreover, children with albinism are still being sent by their families to some of these shelters. In addition, some adults with albinism have chosen to live in such places, and students in secondary school or college have no choice other than to return to them during school holidays either for security reasons or because they have been abandoned by or could not trace their families.

76. Considerable efforts have been made by civil society and the Government since the visit of the African Committee of Experts on the Rights and Welfare of the Child in August 2015, particularly with regard to reducing overcrowding in select shelters. Efforts in that regard began in 2016 in seven regions and involved local authorities and civil society organizations representing persons with albinism. At least 65 children have been reunited with their families; however, many children whose families were identified and contacted in this process opted to go home only for short-term visits or during school holidays, as they do not feel safe at home for longer periods. In the shelters visited by the Independent Expert, a relatively large number of children with albinism are still staying during the holidays. The process of reducing the number of persons with albinism in shelters and reuniting them with their families could be slowed or halted by the risk of attacks outside the shelters, the lack of adequate protection, health and education structures in local communities and the lack of sensitization of families or receiving communities.

77. In addition, reducing shelter populations is complicated by the absence of a registration and family-tracking strategy. In some cases, locating family members of some of the children with albinism brought to the shelter at the peak of the attacks is problematic, as they arrived with no birth certificates and, given their young age at the time, do not remember their place of origin. The intervention of the Tanzania Albinism Society and other organizations in this process has been fundamental in facilitating family reunification and visitation. However, this is a long-term process that requires more governmental and non-governmental support and resources.

78. Transferring children with albinism from shelters also took the form of finding additional boarding schools, including private schools, for some of the children. The number of de facto shelters therefore seems to be growing. A list of all existing shelters,

along with the number of students with albinism in them and relevant services available to them, should be securely shared with all stakeholders, including social workers and other front-line service providers.

79. More remains to be done to enhance the living conditions in shelters. Projects such as the one to build a new dormitory in Buhangija School or to provide new mattresses at Lake View School should be priorities. Other basic measures ought to be taken, including ensuring adequate food supplies to all residents in the shelters, children and adults alike. In addition, some shelters visited have severely overcrowded classrooms, with more than 100 students per class. This overcrowding has a negative impact on the quality of instruction, particularly for children with special needs, including those with albinism.

80. One of the key priorities, given the precarious safety situation of persons with albinism, particularly in rural areas, is to educate and sensitize communities and families of persons with albinism. This includes close cooperation with security committees at the district and ward levels, the provision of basic security items such as mobile phones and the structural reinforcement of unsecured homes by ensuring that they have doors and locks. In addition, mobilizing communities goes beyond an immediate protection strategy and should include long-term strategic awareness-raising to demystify the condition of albinism, increase social inclusion and ensure that adequate structures are in place to support persons with albinism, including to facilitate their integration in local schools and access to health services.

D. Health

81. Because persons with albinism have reduced levels of melanin or colour pigment or none at all, they are particularly vulnerable to skin cancer. Consequently, in a number of countries, skin cancer is reported to be the number-one killer of persons with albinism. Chemotherapy and radiotherapy are available in the country. The Tanzania Albinism Society has its offices at Ocean Road Cancer Institute, which specializes in treating skin cancer. This proximity illustrates the importance of access to health for persons with albinism.

82. However, the cost of diagnostic services and travel to hospitals, given the poverty in which many persons with albinism live, is one of the main barriers to access to health care. Those who are poor and likely to need treatment the most are the least likely to receive it.

83. The result is that persons with albinism, many of whom lack knowledge of preventive measures, may seek medical support only as a last resort, often when it is too late for treatment to succeed. The average age of persons with albinism diagnosed with skin cancer is about 35, a very early age, given the time skin cancer takes to develop. A number of the Independent Expert's sources, themselves persons with albinism, reported the significant frequency of deaths of persons with albinism before the age of 40. Such early deaths are preventable through low-cost measures, including the use of long-sleeve shirt, wide-brimmed hats and sunscreen. To increase awareness, the Government should consider rolling out a national skin cancer prevention strategy, similar to strategies that have been rolled out for other forms of cancer plaguing Tanzanians.

84. The Independent Expert welcomes the inclusion of sunscreen on the list of priority medicines and in the health kits delivered to all hospitals. However, to ensure a regular supply, local production of sunscreen ought to be supported. In particular, the Government should invest more substantively in initiatives such as that undertaken by KiliSun and facilitate efforts to import the relevant raw materials.

85. Although vision impairment varies in severity from one person with albinism to another — and often in proportion to the residual pigment in each person — States have a duty to provide reasonable accommodation to persons with albinism in order to ensure de facto equality with others. Free clinical assessments should be provided by ophthalmologists to persons with albinism. Glasses and adaptive devices should also be provided.

86. In this regard, the Regional Dermatology Training Centre/Standing Voice mobile clinic model is a best practice and should be replicated across the country. In addition to dermatological services and the distribution of K.I.S.S.I.E. (to clients living with albinism and assistive devices to persons with albinism and visual impairment) twice a year in specific regions and districts. As these clinics provide critical health and vision services to persons who would otherwise not have access to such services and thus save lives, it is fundamental to increase the support they receive, strengthen their public-partnership structure and broaden the scope of services they provide, thereby enabling them to reach many more persons in need.

E. Education

87. The country's Inclusive Education Strategy (2012–2017) was adopted to ensure that all children had equal access to quality education in inclusive settings. The aims included ensuring that teachers were able to respond to the diverse needs of learners and that educational support was available to all learners. In addition, the new education and training policy, adopted in 2014, seeks to increase access to educational facilities for children with disabilities, including children with albinism.

88. However, children with albinism cannot benefit from the Strategy if they are not provided with necessary reasonable accommodation, including visual aids such as glasses, monoculars and large-print material. The Government has recognized that there is a shortage of assistive devices for persons with albinism, a gap that is being partially filled by civil society organizations.

89. As with sunscreen, domestic production of such devices would ensure their accessibility, affordability and availability. The Prime Minister's Office, it should be noted, has instructed the Ministry of Industry and Trade to produce assistive devices for persons with disabilities. Not all such assistive devices can be produced domestically, however. The Independent Expert therefore welcomes the instructions given to the Ministry of Industry and Trade by the Prime Minister's Office to reduce the cost of importing assistive devices for persons with disabilities, including persons with albinism. The Independent Expert notes, however, that many items needed by persons with albinism, such as monoculars or glasses, are being imported primarily by civil society organizations and that it is important for the Government to encourage those initiatives by expediting import processes and facilitating the refund of import taxes and duties on such goods.

90. In addition, the overcrowding of classrooms in certain schools used as shelters for persons with albinism significantly complicates the full implementation of the inclusive education policy. Similarly, discrimination against and bullying of children with albinism are still problems in the country's schools. Children with albinism thus drop out of school, with significant consequences for their life expectancy, as a lack of education often means working outdoors in the sun and/or living in poverty, which is often synonymous with living in an insecure home.

91. Furthermore, given the importance of indoor work for the health and safety of persons with albinism, efforts should be made to include persons with albinism in vocational training opportunities, regardless of their academic performance.

F. Socioeconomic situation of persons with albinism

92. A baseline survey conducted by the Tanganyika Christian Refugee Service in the regions of Mwanza, Simiyu, Geita, Shinyanga, Tabora and Dar es Salaam shows that the socioeconomic situation of persons with albinism in the United Republic of Tanzania remains highly challenging and requires substantial intervention. The Tanzania Albinism Society shares these concerns.

93. Officials have indicated that the socioeconomic situation of persons with albinism has a direct impact on their access to medical services, such as skin cancer treatment, and to prevention measures such as sunscreen, hats and protective clothing. It also has a negative

impact on their access to education, as families of children with albinism may not be able to afford the indirect costs of the precautions their children would often need for the long walk to the closest school. In addition, discrimination reportedly has a direct impact on the employment of persons with albinism, as it is difficult for them to sell goods in the marketplace and provide services, given the widespread stigmatization they face. Similarly, it was stressed that only a few persons with albinism are involved in the formal economy.

64. Moreover, poverty is both a result of discrimination against persons with albinism and a root cause of attacks against them. A case in point are those persons with albinism, particularly in rural areas, who are unable to afford basic security features on their homes, such as doors and locks, and can only afford property located a significant distance from the rest of the community.

65. The combination of myths and attacks has also led to cases of discrimination in housing, as some persons with albinism have trouble finding homes to rent, both because property owners fear attacks and because there is considerable stigma attached to albinism. Fear continues to threaten the lives and livelihoods of many persons with albinism, particularly in rural areas. Unable, for security reasons, to store their houses before sunrise or after sunset or work in their fields, their socioeconomic situation, often already made precarious by discrimination, further deteriorates. Persons with albinism should therefore be covered by programmes established by the Government to combat poverty, including through special measures and affirmative action. Similarly, it is important to fully implement the quota established by the Persons with Disabilities Act (2010), under which persons with disabilities are expected to account for 3 per cent of the payroll of companies employing more than 20 people. Raising awareness of the Act among persons with albinism and employers should be a priority of the Government.

V. Conclusion and recommendations

66. **In recent years, the combination of measures taken by the Government and civil society has led to a significant decrease in the number of reported attacks against persons with albinism in the United Republic of Tanzania. However, that progress is highly tenuous, as the root causes of the attacks have not been fully addressed. In addition, the consequences of the surge in the number of attacks are still felt, as demonstrated by the continued use of shelters by persons with albinism. In general, fear continues to plague the lives of persons with albinism, particularly in rural communities.**

67. **Renewed political will and corresponding efforts are necessary to address the underlying causes of attacks, including discrimination, myths, witchcraft and poverty. Long-term commitment is necessary to ensure that current gains are not lost and that the fragile peace attained does not fall apart, taking with it more lives, limbs and dignity.**

68. **The primary responsibility for ensuring that persons with albinism are able to enjoy their human rights rests with the Government, and its strong and continued engagement is essential if the gains that have been made, particularly with regard to safety, health, education and awareness, are to be secured.**

69. **The need for a government champion on the issue resonated in discussions with nearly 50 interlocutors. The reassignment of the former Deputy Prime Minister with albinism to other duties was noted by all. An intergovernmental champion plays a crucial role in coordinating efforts and ensuring resources. Finally, the presence of a person with albinism within the Government championing this issue is a best practice in the region and promises to give long-term effect to government initiatives on the matter.**

Data collection

70. **The Independent Expert recommends that the United Republic of Tanzania:**

(a) Continue to cooperate with Tanzania Albinism Society in efforts to collect data on persons with albinism, including through existing databases and projects;

(b) Ensure that all data collected relating to the situation of persons with albinism are disaggregated at least by sex and age;

(c) Provide adequate safeguards for all data collected on persons with albinism to prevent misuse for attacks, discrimination or other illicit acts.

A comprehensive approach to the enjoyment of human rights by persons with albinism

102. The Independent Expert recommends that the United Republic of Tanzania:

(a) Ensure that a coordinated, multisectoral and comprehensive approach is taken to the enjoyment of the human rights of persons with albinism by strongly supporting the strategic plan developed by the task force working to combat the killings and abduction of persons with albinism. The strategic plan effectively mirrors the Regional Action Plan on Albinism in Africa (2017–2021), a plan promoted by the Independent Expert and recently endorsed by the African Commission on Human and Peoples' Rights;

(b) Promote persons with albinism as role models, or champions, to facilitate the visibility and coordination of different actions taken, including through the nomination of a person with albinism to a high-level position in Government. Such visibility is important to ensure their full integration and combat myths that dehumanize them.

Legislative framework

102. The Independent Expert recommends that the United Republic of Tanzania:

(a) Continue registering practitioners of traditional medicine and monitor their work comprehensively and regularly, while sanctioning practices that do not fall within the existing legal framework;

(b) Use the ongoing review of the Witchcraft Act and the Traditional and Alternative Medicines Act as an opportunity to reflect on witchcraft in the country, take steps to mitigate its root causes and prevent the harmful practices it leads to;

(c) Submit its initial report to the Committee on the Rights of Persons with Disabilities;

(d) Review the legislative framework to ensure that existing provisions on possession of body parts sufficiently address trafficking of body parts of persons with albinism;

(e) Ratify the Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment.

Law enforcement

103. The Independent Expert recommends that the United Republic of Tanzania:

(a) Strengthen community policing by ensuring that adequate resources are provided and by facilitating the reporting of incidents to the police and the gathering of evidence;

(b) Strengthen the role of security committees in each village and ensure that they are trained to report attacks against persons with albinism without delay;

(c) Facilitate international law enforcement cooperation with neighbouring countries, for example through memorandums of understanding, shared databases and extradition treaties.

Reporting of cases

104. **The Independent Expert recommends that the United Republic of Tanzania:**

(a) **Continue promoting cooperation between the authorities and civil society with a view to addressing attacks, including through joint missions to collect, compare and assess information on cases;**

(b) **Continue developing strategies and ways to facilitate the reporting of cases, and ensure prompt follow-up to reports of attacks;**

(c) **Inform victims and/or their families of the outcome of cases that are being or have been investigated and prosecuted;**

(d) **Ensure that the right to freedom of expression, including through the media, applies fully to efforts to report or otherwise publicize cases of attacks against persons with albinism.**

Investigation and prosecution

105. **The Independent Expert recommends that the United Republic of Tanzania:**

(a) **Ensure the judicious use of legislation to fully address all types of attacks against persons with albinism, including those involving possession of body parts;**

(b) **Ensure that all cases of offences against persons with albinism are promptly and thoroughly investigated and documented, with a view to identifying and prosecuting the masterminds of attacks and the chain of perpetrators.**

Shelters

106. **The Independent Expert recommends that the United Republic of Tanzania:**

(a) **Gather, in cooperation with civil society organizations, comprehensive information on all shelters used for the protection of persons with albinism to facilitate a comprehensive and coordinated effort to reduce shelter overcrowding, reunite families and ensure that persons with albinism in these shelters have access to basic services;**

(b) **Continue improving living conditions in shelters, including by ensuring an adequate food supply, conducting thorough assessments of specific needs at each shelter and meeting those needs promptly.**

Awareness-raising

107. **The Independent Expert recommends that the United Republic of Tanzania:**

(a) **Raise awareness of albinism to combat rampant myths about the condition through far-reaching campaigns sustained continuously for at least two years. The campaigns should be in all national languages, involve persons with albinism and target communities in rural areas in particular. They should also involve key stakeholders, including traditional authorities and faith-based organizations;**

(b) **Educate and sensitize communities and families of persons with albinism who have been placed in shelters, with a view to facilitating their safe return and reintegration;**

(c) **Enhance cooperation with security committees at the district and ward levels, providing basic security items such as mobile phones, contributing to the structural reinforcement of unsecured homes by ensuring that they have doors and locks and facilitating the safe return of children with albinism from shelters;**

(d) **Mobilize communities to tackle myths about albinism and ensure that adequate structures are in place to support persons with albinism, including to facilitate their integration into local schools and ensure they have access to sunscreen and health care, all to ensure the safe return of children with albinism from shelters.**

Health

108. **The Independent Expert recommends that the United Republic of Tanzania:**

(a) **Ensure that sunscreen is available, including by providing strong support for domestic production within the framework of the ongoing multi-stakeholder partnership involving the Regional Dermatology Training Centre, KiliSun and Standing Voice, and facilitate the importation of relevant raw materials;**

(b) **Support and significantly extend the reach of early intervention and detection programmes, including through mobile clinics;**

(c) **Provide training and information on albinism and related health issues to mothers of children with albinism and their families immediately after the births of their children to ensure that their skin and vision are adequately protected;**

(d) **Continue to facilitate access to skin cancer treatment, including chemotherapy and radiotherapy, by reducing indirect costs or, where necessary, by providing financial support to ensure prompt access to treatment;**

(e) **Provide free clinical assessments, both dermatological and ophthalmological, to persons with albinism, along with glasses, adaptive devices and other visual aids, within the framework of efforts to provide reasonable accommodation and fulfil international obligations regarding their right to the highest attainable standard of health;**

(f) **Consider rolling out a national skin cancer prevention strategy similar to those that have been rolled out for the 10 other kinds of cancer most commonly affecting Tanzanians.**

Education

109. **The Independent Expert recommends that the United Republic of Tanzania:**

(a) **Ensure full implementation of the inclusive education policy, not least by allocating the necessary resources;**

(b) **Ensure the provision of reasonable accommodation to students with disabilities by making low vision aids, adaptive devices and large-print materials available in all schools;**

(c) **Ensure the systematic training of teachers on the special needs of children with albinism, who should know that children with albinism should be seated in the front row, that such children should be given teachers' notes, that large-print writing should be used on the blackboard and that other teachers and students should learn about albinism;**

(d) **Ensure that schools that have children with albinism are equipped with the necessary basic protections, such as fences, and that teachers and staff are aware of the situation of students with albinism and trained to respond adequately;**

(e) **Facilitate access to vocational training opportunities, so that persons with albinism, regardless of their performance in academic subjects, can prepare for careers that would allow them to work indoors and lift themselves out of poverty.**

Socioeconomic situation

110. **The Independent Expert recommends that the United Republic of Tanzania:**

(a) **Ensure that persons with albinism are covered by the Government's anti-poverty programmes, including through special measures;**

(b) **Enforce the quota established by the Persons with Disabilities Act (2010), under which persons with disabilities are expected to account for 3 per cent of the payroll of companies employing more than 20 people, and raise awareness of the Act among persons with albinism and employers.**

Victim support

111. The Independent Expert recommends that the United Republic of Tanzania continue to provide psychosocial, medical and legal assistance to persons with albinism who are victims of attacks, survivors and their families, while taking into account their specific needs and international human rights standards.

Participation

112. The Independent Expert recommends that the United Republic of Tanzania continue involving persons with albinism in all decisions and measures taken for the full implementation and enjoyment of their rights.

International cooperation and assistance

113. The Independent Expert makes the following recommendations:

(a) International development partners should support national efforts by integrating the issue into development programmes for persons with disabilities, older persons and groups in vulnerable situations, including those discriminated against on the basis of colour, women and children;

(b) The United Nations system should consider providing technical assistance and support to the United Republic of Tanzania in particular for the implementation of the strategic plan developed by the task force responsible for issues related to persons with albinism;

(c) Regional partners should enhance international cooperation to address the human rights challenges faced by persons with albinism, including through the Regional Action Plan on Albinism in Africa and the inclusion of the issue on the agenda of regional and subregional meetings. As many of the issues faced by the United Republic of Tanzania in addressing matters regarding persons with albinism are regional, transnational cooperation, joint action and exchanges of best practices are fundamental.